Crip Contours: Space and Embodiment in 21st Century American Disability Poetry of Jim Ferris,
Stephen Kuusisto and Laurie Clements Lambeth

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Doctor of Philosophy

University of York

English and Related Literature

September 2020
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Abstract

This PhD will interrogate the poetry of Jim Ferris, Stephen Kuusisto and Laurie Clements Lambeth and explore their work’s relationship with space. Their work engages the attention of fellow poets, academics and readers in conversations which challenge established ideas about embodiment, space and community through a focus on their own personal experiences. I argue that the 1990 Americans with Disabilities Act (ADA) legislation, the temporal starting point for this project, placed a renewed focus on how society and theorists think about space in relation to disability. I examine how the three poets use innovative metaphors of space to explore the transition from being a young person to an adult and to articulate the physical, psychological, emotional impact of medical, societal and cultural conceptions of disability that intersect and define their sense of self. I trace space through the institutional spaces of the hospital in the verses by Ferris, in the representations of space in the natural and cityscapes in the poetry of Kuusisto, and in the various poetic works by Lambeth which focus on her evocation of the body. To this end, I employ a new literary spatial concept of “crip contours” which I define as an original way of seeing space from a crip perspective. The term is expressive of the spatial outlines contained in the form of outer and inner corporeal surfaces and the meeting points where bodies intersect with objects, others and their situated practices. I demonstrate how a crip perspective can be understood as an alternative way of perceiving the spaces of the body as a form of “crip contour” which are re-imagined and reconfigured by contact with disability. I explore how these “crip contours” work in the poetry of Ferris, Kuusisto and Lambeth.
Abbreviations


DTF: Vassar Miller, *Despite the Flesh* (U of Texas P 1985)


HP: Jim Ferris, *The Hospital Poems* (Main Street Rag 2004)


OB: Stephen Kuusisto, *Only Bread, Only Light* (Copper Canyon Press 2000)

P: Stephen Kuusisto, *Planet of the Blind* (Faber and Faber 1998)

VB: Laurie Clements Lambeth, *Veil and Burn* (U of Illinois P 2008)

SG: Jim Ferris, *Slouching Towards Guantanamo* (Main Street Rag 2011)

SPGMH: Selected Poems of Gerard Manley Hopkins (Dover Publications 2011)


Acknowledgements

First and Foremost, I would like to thank my supervisor Dr Alice Hall whose guidance and support throughout this project has been absolutely invaluable. I am extremely grateful to Dr Matthew Campbell for his insights and guidance over the course of this study. I also want to show my appreciation to Dr JT Welsh for his help during the study especially during my second year. I would like to say a very big thank you to Pat Middleton and Moira Niven for their generous encouragement during the project. Deepest thanks to Darcy, Madeline, Katy, Veronica, Tilly, Dorothy and Francesca for their friendship during my time studying at University of York.

This study was made possible by funding from the Student Awards Agency for Scotland which provided grants for mentoring and typing support. I would like to say thank you to Catherine for helping me throughout this project.
Declaration

I declare that this thesis is a presentation of original work and I am the sole author. This work has not previously been presented for an award at this, or any other, university. All sources are acknowledged as references, and all works consulted in the course of this study are included in the bibliography.


My recent interviews with Jim Ferris, “Interview with Jim Ferris ” and Daniel Sluman, “Interview with Daniel Sluman,” have both been accepted for publication by Wordgathering.com and are due to appear in the September (2020) issue.

I wish to say a huge thanks to the poets Jim Ferris, Stephen Kuusisto, Laurie Clements Lambeth and Daniel Sluman for agreeing to be interviewed for this PhD project. I am extremely grateful for the time they have given to discussing their thoughts and experiences and allowing me to include these conversations within this project. The full interviews are included in the appendices.
Thesis Introduction: Towards an American Aesthetic of Disability Poetic

This thesis considers the relationship between embodiment and space in the poetry of three 21st century American disability poets: Jim Ferris, Stephen Kuusisto and Lauri Clements Lambeth. I draw on their published poetic memoirs, online blogs, video recordings, academic essays and prose fragments. The three award-winning poets have been selected because they are part of a unique group of disability theorists, essayists and university intellectuals currently engaged in theoretical discussions and poetic representations of disability, contributing to debates on space, embodiment, autobiography and the role of poetry. Their work engages the attention of fellow poets, academics and readers in conversations which challenge established ideas about embodiment, space and community through a focus on their own personal experiences. As scholars, writers and disability poets, they “choose” their “word(s)” carefully and their poems “swagger” in lines that celebrate and reclaim the notion of difference (Nancy Mairs “On Being a Cripple”). Their poems challenge predefined social constructs, presenting an acute sense of otherness; even when this otherness is not visible, it is inherently present.

Ferris’s concerns, like those of Kuusisto and Lambeth’s poetry, extend beyond misrepresentation of the personal and local experience to express hope for the inclusion and liberation of disabled persons of all nations. The later poetry of Ferris and Kuusisto in particular, problematise the boundaries of autobiographical poetry, shifting to semi-autobiographical representations of experience. They ultimately widen the speaker’s situational context, evolving as interpreters of lived reality for the disabled community and as prophets of potentiality in new and future spaces for all humanity. Ferris’s prayer-like poem “For the Betterment of Humanity,” expresses private desires in public terms as an incantation, subverting political, social and medical ideals by praising atypical bodies:

Save us from the tyranny of the norm.

Blessed are the unfit, the twisted, the shamed,
Blessed are the naked and the nude.
Blessed are they who will not get better.
Blessed are those who shock the pool.
Save us from the saviours, from your saints,
From those who know what’s best. Save us from progress –
Some day we may Get Better.

//

Save ourselves from what’s above, while we
Save ourselves, at last, from you. (STG76 33-46)

The accumulative rhythmical regularity and repetitive phrasing of “Blessed” and “Save us” is triumphant in tone recalling Walt Whitman’s psalmist refrains. The anaphora cadence and listing style of biblical rhetoric distils from the “us” and “we” to the final line’s end-stopped unspecified “you” (STG76 46). The patterning of curated language is disrupted by the altered viewpoint; the reader finds the concluding focus is centred on them and directed towards anticipating their future acts. Thus, Ferris reveals the power of poetry to involve readers interactively. He engages us in thinking about the range of misconceptions around topics of physical, motor, sensory and cognitive difference.

Despite the burgeoning of disability studies over recent years, the work of Ferris, Kuusisto and Lambeth remains underexplored, especially in relation to their representation of the political and geographical interrelations of bodies negotiating space. As Ferris comments, “my disability experience deeply informs how I encounter the world, how I think and feel as I inhabit each day in whatever place I am in on this complex planet. I am using that disability experience whether I write ‘about disability’ overtly or not” (Appendix 1 269). My study seeks to give greater prominence to the role of poetry in cultural disability studies by focusing on the diverse, innovative and transformative poetic representations of atypical bodies in relation to notions of
space. Through their poetry, I explore the question of how poetry can reshape understandings of non-normative embodiment through figurative and structural representations of “bodily contours” and the real and imaginary spaces they inhabit. I want to suggest that their poetry of opens up these complex spaces and attempts to respond to questions on embodiment in creative new ways; they experiment with metaphor as a de-familiarising technique and use graphic typographical representations to reshape notions of embodiment, stimulate thinking about stigmatisation, and engage others in considering their own relationship with the world around them.

A key argument of my study, therefore, is that these poets all insist upon the importance of making space for disability discourse in a public arena. Ferris emphasises that aesthetic and political agency is a key priority for him in the process of writing his poems: “I want to engage in conversation . . . But I also want to engage my fellow crips, my brother and my sister poets, and our contemporaries in the larger culture and the larger world. Ambitious? You bet. Because I still think that poetry can change the world” (Jennifer Bartlett et al. Beauty is a Verb 92). Ferris writes that whilst such changes “may seem impossibly small - a phrase here, a feeling there, an idea that may eventually find fertile ground,” disability poetry has a capacity for opening up spaces on the page, within the walls of the academies, and in policy debates of the future (“Keeping the Knives Sharp” 92).

Currently, Ferris is employed as a Professor and Ability Center Endowed Chair in Disability Studies at University of Toledo; Kuusisto is a professor at Syracuse University where he is Director of Interdisciplinary Programs and Outreach in the city of New York; and Lambeth holds a Creative Writing post in Honors College Faculty at the University of Houston. Yet, their work reaches beyond the confines of the institutions they all inhabit as university teachers by contributing critically to the fields of literary studies, medical humanities, creative writing and disability theory. They are all part of a self-conscious “disability poetry” movement, writing
today as American academics, and all in communication with each other. They are part of an ongoing dialogue working as critics and public intellectuals, conversing with other specialists, their audience of readers and students, including myself, as well as publishing privately as poets and memoir writers.

Ferris’s first collection, *The Hospital Poems* (2004), winner of the International Main Street Rag Poetry Book Award, made him widely known as a so-called “poet of cripples” (Sami Schalk “Disability Poetry Power” 1). His article, “The Enjamed Body: A Step Toward a Crippled Poetics” (2004), is recognised as a foundational work in developing a critical theory of disability poetry. Poems from his chap book, *Facts of Life* (2005), are reproduced in his second major collection of poetry, *Slouching Towards Guantanamo* (2011). In his 2007 essay “Crip Poetry, Or How I learned to Love the Limp,” Ferris explains that his sense of self and that of other disability poets such as Kuusisto and Lambeth, “comes from the outside, it comes from the abnormal, it is centered in the experience of being out of the ordinary” emphasising the spatial nature as a fundamental characteristic of crip poetry (“Crip Poetry”).

Like Kuusisto and Lambeth, Ferris writes about the agency of his poetry and its capacity to effect cultural change: “Poetry offers readers and listeners new opportunities to feel, think, experience something in this world that we share. When we’re lucky, poems give us not only new opportunities but new ways of feeling/thinking/experiencing” (Appendix 1 270-271). Ferris’s poetry expands these “new ways” often with imagery extensively related to his mobility disability and time spent in and out of hospitals where medical professionals attempted to cure his asymmetrical physique by surgically altering his physical way of being in the world (Appendix 1 270).

Poet’s Journey (2018). These collections, and his two poetry collections, Only Bread, Only Light (2000), and Letters to Borges (2013), are accompanied by over ten years of the online blog “Planet of the Blind: It’s not as dark as you think . . .” as experiences with blindness recounted on his website “stephenkuusisto.com.” Born three months premature with Retinopathy of Prematurity (RPO), a condition that leads to scarred retinas and nystagmus, or eyes that dart uncontrollably meant he endured various medical treatments during childhood, adolescence and later as a young adult when a papercut tore his cornea.

In a recent blog entry, Kuusisto indicates how he is still very much concerned with effecting cultural change, highlighting the role that academics have in changing thinking on disability and inclusion. He laments: “I will not be sad today, even though a faculty member recently treated me to unspeakable ableism. He can’t touch me. There are invisible rubies inside my shoulders” (“On Refusing the Sadness Industry”). These observations highlight thematic concerns that recur in the poetry of the selected poets, Ferris, Kuusisto and Lambeth, conveying how they seek to represent the negotiation of oppressive attitudes of ableism. Their imagery depicts the body’s protection from stigma by “invisible” armourings (like Kuusisto’s “rubies”) that lie on or underneath inner and outer surfaces of the skin; these armourings defend the interior psyche against the “touch” of cultural practices that contain and limit conceptions of difference (“On Refusing the Sadness Industry”).

Lambeth’s life writing verse and “fragmented” prose collection, Veil and Burn (2008), was the winner of the National Poetry Series award in 2006. It includes several online published poems which have appeared, for example, in the Paris Review, Wordgathering, Crazyhorse, and the Mid-American Review with others anthologised in Beauty Is a Verb: The New Poetry of Disability (2011), and A Face to Meet the Faces: An Anthology of Contemporary Persona Poetry (2012). Lambeth is currently working on a memoir and second collection of poetry, Bright Pane. Her poetry situates the landscape of the body as a space where memories happen and where
interacting emotions are perceived in the fluid interplay of internal and external contours. For her, “both poetry and lyric prose [are] tremendous vehicles to reclaim and re/present embodiment” as unique expressions of atypical lived experience (Appendix 3 285).

Like Ferris and Kuusisto, Lambeth’s poems articulate “the validity and importance of the disabled body and the primacy of disabled experience” (Appendix 3 288). Whilst her creative works are subjective representations of the lived experience of Multiple Sclerosis (MS), a chronic illness often discounted as a disabling condition because of its “invisible” neurological form, they offer insight into many different ways of being in the world. She emphasises the significance of the particular contribution of poetry as a genre: “Poetry can provide an immediate experience of a different body for readers, moving them outside of their own bodies and into that of the poet, feeling something akin to what s/he feels” (Appendix 3 280). Lambeth argues that poetry can imaginatively break down affective barriers at the points where bodies and experiences intersect.

I also examine how all three poets use innovative metaphors of space to explore the transition from being a young person to an adult and to articulate the physical, psychological, emotional impact of medical, societal and cultural conceptions of disability that intersect and define their sense of self. Poems on childhood and teenage experience, for example, detail a need for self-protection against external forces and invisible elements: protection in the form of coverings for the skin and hardened cognitive and physical boundaries document techniques of resistance. The imagery of their poetry is associated with bodily protection, containment, coverings, exposure and physical, psychological vulnerability. Ferris’s poem “Sweet Soul Music” emphasises the fragile nature of these coverings which veil private spheres and desires:

These are the songs that pierce my cover, that call my clan,
That cry in my voice in the clan, in the closeted
Hospital night. But I always want to walk like a man. (HP30 11-13)
Here, the metaphorical surface shields are pierced by “songs” which “call” to fellow “clan” members, other disabled patients confined within the “closeted” spaces of the hospital (HP30 11-12). The songs of home merge with the “cry” of the speaker’s voice making the space a site of conflict (HP30 12). The caesura in the concluding line pivots on the word “But” suggesting tension in the desire to resist and yet also conform to societal expectations of normality.

Emerging from the tense interchange is a sense of testing the limits of self-determination.

In Ferris’s hospital poems, I contend, the body surfaces of the narrator’s naked flesh are exposed, stripped of outer coverings, and contained within the examination room under scrutiny of doctors represented as figures of institutional authority. Kuusisto’s collection of poems also explores isolation, vulnerability and exposure to prejudice, in his case, the particular stigma of ocularcentric views of perception that stereotypically privilege vision over other senses. Lambeth utilises poetry as a medium to document the self-fashioned armouring of the skin as a cover that protects against the eroding force of intermittent symptoms of MS and the feeling of somatic invisibility. These poets explore the relationship between inside and outside through a focus on bodily boundaries, such as the skin, as layered, fragmented and transient spatial surfaces. Chronicling these experiences in inventive poetic forms, they seek to reclaim some control, presenting a more fluid understanding of what it means to have a disability.

As part of the research for this study, I have conducted interviews with all three poets. These feed into my examination of contemporary debates about the much-undervalued role of disability poetry in medical humanities and cultural disability discourse but also in critical discourses on space and spatiality. In examining their reflections on lived experience, this study also contributes to the literary fields of life writing and criticism of contemporary poetry. I offer a unique focus on the importance of space in disability poetry and argue that it is fundamentally concerned with making things visible by expressing a particular interest in an invisibility/hyper-visibility divide through spatial representation. In one sense, disability poetry is concerned with
occupying and being visible in public spaces, claiming space on the bookshelf, in the academy, in cities and towns. In another, they push the boundaries of the autobiographical lyric form to condense the space between poet and reader experience. As Ferris notes:

There is an interesting conflict between conforming to the generic expectations of what a poem should look like and trying to create for the reader and listener an experience that reflects what I’m seeking to engender. In a real way the poems are not about me. They may draw heavily on my lived experience; they are certainly shaped by my thinking and feeling and sense of language; but for a poem to really work, it has to in some way not only be accessible to the audience but also to be in some unexpected way about the audience. . . . And when my poems are really working, they stop being mine and they become yours and ours. (Appendix 1 270)

Their poetry provides a space in which private experience is made public in order to reclaim established cultural narratives of disability and manifest new modes of connection.

To date, little critical analysis of Ferris, Kuusisto, and Lambeth’s poetry or its contribution to the field of disability studies has been published. Despite the significance of their work in establishing a distinctive disability poetry aesthetics as part of a disability poetics movement, the use of their poetry as a discursive tool has largely been subsumed by the generic term of “literature.” This is representative of the way in which poetry as a whole has been largely absent from disability discourse, particularly in relation to space and embodiment. Michael Davidson, for example, in his “Introduction: American Poetry 2000-2009” (2011) omits any reference to disability poets other than to note that digitalising poetry gives access to Deaf readers (625). In the “foundational monographs” of literary disability studies which David Bolt lists in his article “A Brief History of Literary Disability Studies” (2017) as Lennard Davis’s *Enforcing Normalcy: Disability, Deafness, and the Body* (1995), Rosemarie Garland-Thomson’s *Extraordinary Bodies* (1997) and David Mitchell and Sharon Snyder’s *Narrative Prosthesis*
(2000), the wealth and contribution of contemporary disability poetry has been largely overlooked (2). For Kuusisto, omission of poets and their poetry from discussions within the field is reductive: “Disability Studies has seemed to me un-nutritious most of the time, reactive and polemical rather than speculative and probative, though I’m fond of any work proposing disability as epistemology” (Appendix 2 276).

On a more positive note, Lambeth comments “One element of DS that I find very compelling is the way that theorists arrive at observations often through biographical experience, which brings theory into the body and into felt experience, a more private sphere” (Appendix 3 287). Poetry is a particularly powerful vehicle for experimenting with the relationship and integration of ideas of space and embodiment, disability theory, and the poetic “processes of production and reception” (Ian Davidson Ideas on Space 48). For Kuusisto, “Poetry comes unbidden /Bird-like, tapping //At the windows” as these processes interconnect (“Thinking of Sibelius”1-10). Thus in considering the intertwined politics and aesthetics of disability poetry, this study makes extensive use of the writings of the poets themselves as critics and public intellectuals. For example, Kuusisto asks, “What can we learn from poetry about the body and the culture of bodies? Is what we see in a poem merely a figurative illustration of extrinsic historical or political truths or can a poem create a new and unforeseen nexus of identity and consciousness?” (“Creative Writing”). He sets out, therefore, to challenge himself as well as others working in the field of disability discourse and elsewhere. To be clear, Ferris, Kuusisto and Lambeth, are all connected though their status as contemporary American poets whose writing has a strong consciousness of disability rights and a self-reflexive approach to disability studies. The tension between the personal and the political is fundamental to their poetry. They explore the tension between the desire to represent personal experiences of disability and the urge to utilise the art form to make a wider set of political arguments that challenge how individuals are encouraged to view their embodiment by society.
According to Gareth Williams, this debate about the purpose of disability representation in literature has led to the process of writing about disability becoming a “hotly contested terrain in recent years” with “long-standing differences” in the terms people use for describing disability (1194). Indeed, for Irving Zola the language of disability itself has become political through analysis of systems being attached to disability literature analysis and, therefore, “it is increasingly difficult to use terms to describe chronic illness and disability innocently” (1194).

At the same time, Ferris indicates that, while these debates are applicable to his writing, the aesthetic nature of poetry as a creative literary form must not be overlooked. He warns, “Greater access and opportunity for disabled people is a crucial goal, but for poems to work they can’t be propaganda. And we have to be careful about being too directive with these delicate but powerful things” (Appendix 1 272).

Thus, questions about individual experience versus collective activist agendas form a backdrop to disability poetry but, I argue, should not limit its parameters of definition. For Kuusisto, part of the drive behind his poetry is about reclaiming the “public” self (Appendix 2 278). In fact, Kuusisto suggests that it is the tension between the public and private expressed in poetry that allows access to private spaces (the body, the imagination) but brings them into the public sphere through the publication of this material. He also connects these debates to specific literary and poetic forms; Kuusisto emphasises that the lyric, often viewed as a private form, has a broader political significance: “Claiming disability requires claiming the lyric. If people with disabilities have been exiled by history, by the architectures of cities and the policies of the state, then the lyric and ironic form of awareness is central to locating a more vital language” (“Walt Whitman Discovers Disability”). What is more, this agency is one which de-familiarises routine patterns of thinking about subjects. Kuusisto’s poem “Why Poetry Surpasses Your Friends” expresses the ability of poetry to unsettle and reconstruct disparate ideas:

This is a poem with a gut ache and a broken lamp.
It used to be a hole; it used to be a burst tire.

Just so, you’re the only one in the world.

//

The poem knows. (LB17 1-3 6)

The notion of a poem’s capacity to heal all ills is unrealistic; the residual “gut ache” and “broken lamp” suggest an alternative liberating agency whereby poems fill the spaces, reassemble experiences, meaning and thoughts in transformative yet realistic ways. The multiple interchange of forms which shift again from “hole” to “burst tyre,” renders a concise complexity of colloquial language which leaps between associations (LB17 2). Lack of explicit expression about what the poem “knows” introduces an element of mysticism representative of the expansive range and unique potential in “you’re the only one” (LB17 6). The oblique connections problematise what we think we know.

Ferris also seeks to problematise established categories of representations in order to challenge their institutional and cultural logic of production. He conceives his poetry in spatial terms as a meeting point for political and personal agency; he suggests that poetry is a creative aesthetic medium through which the private can be made public, thereby exposing ingrained attitudes and prejudices that are socially produced. He explains that his poetry gives him agency: “Poetry is an important part of what I do and how I think about experiences and respond to the world” (“Crip Poetry”). He later outlines the consequences of not defining disability in the interview “Disability and Poetry” where he remarks: “But if we don’t claim our difference, if we don’t write disability, the normies will keep doing it for us. It is crucial that we don’t keep leaving the field to them, even when we love them” (Bartlett et al. 273). Lambeth’s poem “Burn Fragment” visually represents how emotions, actions and agency are shaped by interactions with others:
One hand holds the other

     thumb over thumb

     tracing circles

and lines as though pacing

to bring it back

through the barrier splitting

wound from its shaping moment

shape from event

that particular now from becoming a

then (lines 16-25)

For Lambeth, the notion that encounters with others shapes difference is illustrated by the diffusion of white space interspersed with the repetitious “thumb,” “shaping” and “shape” forming overlapping threads (15-24). The “shaping moment” is depicted as a fragmented process of “becoming” and resistance, a tension signified in “pacing” and “splitting” and through the enjambed line movement which disconnects “now” from “then” (19-25). Sara Ahmed’s work, *The Cultural Politics of Emotion* (2004) explores how emotions work to shape the surfaces of individual and collective bodies asserting that “Bodies take the shape of the very contact they have with objects and others” in the sense that our actions and reactions are shaped by the points of contact we have with others (*Cultural Politics* 1). Ahmed’s view presents a passive notion of bodies responding to others rather than as bodies actively and materially shaping others and changing thinking by challenging particular modes of perception. By contrast, Ferris refers to a more active political process, one which writes and reclaims difference; his comments call for the creation of a counter-history and an investment in meaning which is transformative and potentially radical politically.
(Re)Defining a Disability Poetics

At this point, I want to make a case for disability poetry as a poetry of spatiality, thereby expanding the notion of what disability poetry is. Ferris expresses the spatial nature of crip poetry declaring that it has “the potential to transform the world, to make the world in which we live roomier” (“Crip Poetry”). He indicates the ways in which his poetry attempts to achieve this aim:

I hope that my poems help to create a space in the social consciousness for disabled people to be – and be recognized - as full, whole human beings. I hope my poems assert the rich and fruitful presence of a wide range of ways of moving through the world. Some of my poems advance an explicitly disabled persona using language to engage with [a]
complex world. (Appendix 1 268)

One example is his poem “How We Swim” which, according to Ferris “is on one level an elegy for the late scholar and activist Paul Longmore, while on another level it is about disability activism and the disability rights movement - about crips insisting that we belong in the world” (Appendix 1 268-269). The 296 line poem calls on readers to rise to the challenge of making space in society for anomalous bodies and concludes with the following pledge:

and so I give

this testament

away, and so the faithful

will give what

faith they have away,

the torch is dropped,

kicked, and picked up —
kiss the battered torch —
this messy march demands
a million marshals,
and so we limp on,
for a time,
strangers to our
families,
family to the strange,
we limp on,
this is how we swim. (DSQ 280-296)

The wavering verse form recalls Mairs’s emphasis on lines that “swagger,” rejoicing in reclaiming the notion of embodied difference (“On Being a Cripple”). The enjambed lines exude a purposeful fluidity, a seemingly intangible organisation of disparate parts. Yet the verse maintains a constant internal connection through overlapping repetitions of “and so” which thread together meaning. The alliterative “messy march” of a “million marshals” and the repetitious overlaps of “limp” “family” and “strangers” all emphasise the interconnectedness of relational encounters. The collective “we” is a sort of composite of bodies reflecting different institutional practices and engagements which yet remain entirely individual due to each body’s singularity of perception and experience. Hence Ferris comments on the need for a balanced, flexible approach:

Other poems may seek to poke holes in the tissue of attitudes, assumptions and practices that serve to otherize and impinge on the humanity of disabled people. Still other poems are not “about disability” in any overt external sense, but the simple presence of poems by a disabled poet helps to claim space in the world for disabled people and their rich and varied perspectives. (Appendix I 269)
This thesis takes up the challenge posted here by Ferris, by examining the relationship between disability activism and a canon of disability poetry that explores the relationship between individuals, their complex encounters and engagement with space.

Significantly, existing definitions of American disability crip poetics often originate from Ferris’s seminal work in the field where he establishes the defining characteristics of the genre:

Disability poetry can be recognized by several characteristics: a challenge to stereotypes and an insistence on self-definition; foregrounding of the perspective of people with disabilities; an emphasis on embodiment, especially atypical embodiment; and alternative techniques and poetics. (Gary Albrecht et al. 1252)

This definition, first printed in the authoritative Encyclopedia of Disability (2006), reappears in “Crip Poetry, or How I Learned to Love The Limp” (2007) and is replicated in Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies (2018). My study, therefore, seeks to open up the space for an expansion of this definition of the disability poetry canon. It makes the case for inclusion of a fifth element: the emphasis on navigating different spaces, both real and imagined, and the notion of what I term “crip contours.” This allows for consideration of the various meeting points that Ferris asks us to consider when he poses the following rhetorical questions:

But what would it mean to have a different starting point, a different foundation, a different center . . . or to have no center? What would it mean to live in a world that understood asymmetry as a prime characteristic? To live in a world sensitised by a crip aesthetic? (“Keeping the Knives Sharp” 90)

These different starting points encourage alternative perspectives, emphasising the ability of individuals to rethink and ultimately reshape the outlines of embodiment. In order to conceptualise lived experience, the three poets, I argue, articulate the diverse ways in which non-normative bodies negotiate and reimagine different notions of space. Private psychical interiors
and biological surfaces are re-examined in relation to the contact of external environmental and cultural influences depicted spatially as intersecting meeting points of situation and cultural location connecting with different bodies. I demonstrate how a crip perspective can be understood as an alternative way of perceiving the spaces of the body as a form of “crip contour” intersecting the liminal, interstitial, real and conceived spaces which are re-imagined and reconfigured by contact with disability. Individuals are therefore represented as interconnected beings shaped by experience and their environment. I explore how these “crip contours” work in the poetry of Ferris, Kuusisto and Lambeth.

These three selected poets rethink the relationship between the inside and the outside of the subject and traverse different geometrical planes in their poetry. In Foucauldian terms, space “draws us out of ourselves, in which the erosion of our lives, our time and our history occurs, the space that claws and gnaws at us, is also, in itself, a heterogeneous space” (“Of Other Spaces” 25). For Ferris, Kuusisto and Lambeth, this erosion of the self is represented in diverse ways, for example, through overlapping layers of literary allusions, fragmenting citations into a collage of reassembled images, and juxtaposing contemporary with traditional cultural references. Michel Foucault adds:

In other words, we do not live in a kind of void, inside of which we could place individuals and things. We do not live inside a void that could be colored with diverse shades of light, we live inside a set of relations that delineates sites which are irreducible to one another and absolutely not superimposable on one another. (“Of Other Spaces” 23)

If we accept Foucault’s premise that we do not live in a “void” of space and that the spaces we inhabit are bounded by “sites” and “relations” that delineate the “inside,” and therefore, map the outside, then we can imagine and re-imagine the representation of those meeting points according to the contours of differently abled bodies, moving and negotiating these “irreducible” sites (“Of Other Spaces” 23).
Poetry provides a flexible medium through which such complex spatial perspectives can be articulated. Indeed, Ferris comments on the capacity of disability poetry to disrupt from “inside” the lived spaces by validating marginalised experience of otherness, when he observes: “Poetry seeks to explore and validate the lived experience of moving through the world with a disability” (*Encyclopedia of Disability* 151). Reading from a disability perspective opens up our thinking on embodiment and how bodies negotiate the world. In this way, negotiation of space is remapped and reimagined and all three poets insist on the interconnection between interior and exterior spaces. I argue that collectively, their approach is one of creating, reconfiguring, and interweaving imagined spatial geographies with images and experiences of physical spaces. Thus a key concern of this thesis is the examination of the ways in which disability poetry opens up spaces to embrace the multiple, ambiguous, fluid relationships between the poet and their geographical, architectural and cultural setting: Ferris interrogates his relationship with the hospital as a building and an institution; Kuusisto develops a new understanding of the natural and city landscapes that surround him; and Lambeth articulates the ongoing experience of living in a body, her body, that has MS. Space is an important aspect of how disability is conceptualised, analysed and critiqued. I argue that the 1990 Americans with Disabilities Act (ADA) legislation, the temporal starting point for this project, placed a renewed focus on how society and theorists think about space in relation to disability. Changes in legislative regulations had the effect of making disability more visible and this is complexly played out and reconfigured in the works of Ferris, Kuusisto and Lambeth.

**Disability Poetry and the “Spatial Turn”**

This inquiry extends conversations on the spatial turn in literature as outlined in Robert Tally’s *Spatiality* (2012), a work which, despite giving an overview of the spatial form in prose
narratives, fails to address the specific contribution of poetic experimentation with spatial, structural, syntactical and typographical techniques. Tally’s more recent *Ecocriticism and Geocriticism* (2016), emphasises how literature in general has been concerned with the need to articulate experience through the mode of spatiality: “Literary geography has itself been motivated by intensively political goals, as the need to map the spaces and places of literature appears crucial to the genealogical disclosure or uncovering of formerly repressed narratives” (2). I intend to show how poetry gives creative space in which to challenge the “repressed” representational treatment of people with disabilities so that their function in literary discourse is seen to extend beyond the two functions summed up by Mitchell and Snyder as a “stock feature of characterization” and as an “opportunistic metaphorical device” (*Narrative Prosthesis* 47).

In recent studies where the relationship between poetic practices and spatiality is critiqued, no reference is made to the contribution of disability poetry. In his “Foreword,” Peter Barry argues that Davidson focuses on the 1950s to 1970s and the 1990s work of British and American “neo-Modernist” poets such as Charles Olson, exploring their poetic engagement with space as “language” poets without reference to contemporary disability poets or disability poetics (*Ideas on Space* x). Heather Yeung’s *Spatial Engagement with Poetry* (2015) explores the mapping of place in the work of four late Twentieth century British poets; detailing, for example, Seamus Heaney’s articulation of a “deep-rooted sense of place” in his poetry on Ireland (36).

This thesis does not propose to contest numerous theoretical, philosophical and phenomenological conceptions of space. Instead, it limits the parameters of study by referencing the spatial theory of a select few such as Henri Lefebvre’s *The Production of Space* (1991) as Davidson does in *Ideas on Space in Contemporary Poetry* (2007). Lefebvre’s theories about bodies, space and power relations are most relevant to this study because I explore the notion of the atypical body in and of spaces. Specifically, representations of bodies negotiating spaces, coming into contact with other objects and practices, and the spaces of the body, inhabiting and
being affected by contact with external forces. Lefebvre argues that to understand the body we must engage with the interchanging movements of bodies with spaces:

Space – my space – is not the content of which I constitute the textuality: instead it is first of all my body, and then it is my body’s counterpart or other, its mirror image or shadow: it is the shifting intersection between that which touches, threatens or benefits my body on the one hand, and all other bodies on the other. Thus we are concerned, once again, with gasps and tensions, contacts and separations (184).

He draws attention to the connection between spatial practices and the performances within space, highlighting that space is not a vacuum but is shaped by pre-existing political and societal organisational actions and meanings. Spatial practices are dominated by behavioural customs which perpetuate traditional rituals, linking the experience of individuals to the practices and meanings within the contexts of the particular space. It then follows that where ableist thinking and societal practices dominate, ableist notions of space and embodiment are also conceived from an ableist perspective.

Lefebvre also asserts that the body is both a space and is governed by the determinants of the space it resides in: “A body so conceived, as produced and as the production of space, is immediately subject to the determinants of that space . . . the spatial body’s material character derives from space, from the energy that is deployed and put to use there” (195). I examine the relationship between disability poetry and activism as one that disrupts ableist determinants of bodies and spaces. I explore crippled representations that unsettle notions of “spatial competence and performance,” of bodies resisting the practices within spaces, and reclaiming the language that encodes some bodies as less productive (Lefebvre 38). Davidson summarises the interrelationship of bodies and space:

There are two principal approaches to the study of the body; that of the body in space, and the way the body “produces” space through perspective, scale and travel, and that of
the space of the body itself, both its internal space and the surface of the skin. Within spatial practice they function conditionally; the body in space produces the space of the body, and cannot be conceived as existing without it. (*Ideas on Space* 41)

I offer a spatial perspective of disability poetry and embodiment that can be envisioned as part of the broader examination of the role of space in spatial studies. I adopt Davidson’s definition of “what space is” as a useful framework for this study rather than attempting to provide new insights into the nature of space itself:

> Space is both lived and conceptualized. In other words, we have an embodied experience of space a (sic) well as a mental concept of space. The sense of where we are is a combination of that immediate embodied experience and the concept of our location within a larger picture, shifting our perceptions from the phenomenologically encountered experience to the larger geographical and social structures we are part of. (*Ideas of Space* 33)

Poetic representations of lived and conceived spaces are shown to be subverted to undermine ableist conceptions of reality and ways of perceiving space.

> In this way, the poems, the poetic language and the voices of the poets remain the focal point. Indeed, I follow Ferris’s recommendation not to inhibit potential in the trialogue relationship between the poetic language, the poet’s voice and the poem’s reader/audience. When asked about the influence of other theorists in his creative work, Ferris states:

> I find myself using ideas and language from existential phenomenologists like Merleau-Ponty, but I’m leery of too explicitly committing to any theorist’s ideas—I think I’m afraid that will inhibit the poem from jumping wherever the hell it needs to go.”

(*Appendix 1* 274)

The poetic experimentation with spatial metaphors, associative leaps between ideas and unpredictable movement of content and form on the space of the page are characteristic of the
work of Ferris, Kuusisto and Lambeth because they express a self-conscious desire to find new ways of expressing lived embodiment as an ongoing spatial process.

**Ferris, Kuusisto and Lambeth: Space, Activism and Crip Contours**

The main body of this thesis explores how Ferris, Kuusisto and Lambeth investigate the relationship between personal experiences, social and cultural practices, attitudes and institutionalisation processes. I intend to show how they are connected by a crip consciousness, a sense of the relationship between poetry, activism and autobiography and by an interest in space. I examine how each poet interrogates the tension in these relationships through spatial metaphors and experimentation with alternative poetics and structural form. I trace space through the institutional spaces of the hospital in the verses by Ferris, in the representations of space in the natural and cityscapes in the poetry of Kuusisto, and in the various poetic works by Lambeth which focus on her evocation of the body. When Lambeth states “What is inaccessible to most readers offers me access to the world of words, to my world, where poetic lines serve as a form of automatic doors, or elevators, or accessible parking spaces, ramps, lowered countertops,” her concern is to articulate how on the one hand, her poetry attempts to show others the value and strength of a subjective disability experience (“Gaining Access”); on another, to indicate how lines and words are figuratively reimagined as “doors” opening up to give her access to different conceptions of reality, give visibility to the atypical, and de-familiarise the typical. Their work, individually and collectively, broadens our analytical and epistemological perspective by sensitising us to the importance of space in disability poetry as a genre.

To this end, I employ a new literary spatial concept of “crip contours.” I define this as an original way of seeing space from a crip perspective. The term is expressive of the spatial outlines, the lines and borders representing the boundary, shape or form of outer and inner
corporeal surfaces and the meeting points where bodies intersect with objects, others and their situated practices. They connect the liminal spaces where differences between embodied experience and societal practice interface, overlap or move through; the contours, the spatial outlines, the boundaries where architectural, institutional, cultural and political landscapes intersect. They contest and realign the customary boundaries between the private and the public in repeated juxtapositions of body surfaces which challenge normative expectations of embodiment.

My intention is to demonstrate how a crip perspective can be understood as an alternative way of perceiving the spaces of the body and the environment, emphasising intersecting, liminal, interstitial, real and imagined spaces which are reconfigured by contact with disability. When these various contours are depicted as intersecting meeting points, individuals are represented as interconnected rather than isolated beings. In my analysis in the three chapters that follow, I explore how these crip contours work in the poetry of Ferris, Kuusisto and Lambeth. Reading their poems through the concept of crip contours is a fruitful way in which to broaden understanding of the ways in which experiences of disability can influence a poet's work, not only in terms of content, form and style, but in communicating the ways disability policy, architectural and attitudinal barriers impact on the lives of disabled and nondisabled individuals.

Ferris first coins the name “crip poetry” as a term to emphasise the distinctive perspective, agency and voice of disability poetry: “Sometimes referred to as crip poetry, disability poetry embodies a disability consciousness; it is informed by and contributes to disability culture” (“Poetry” 1252). It is this “disability consciousness” that all three poets share and gives a sense of political agency to their poetry. Kuusisto expresses something similar when he states, “the lyric is the mode of poetry that best resists the falsifications of narrative imprinting . . . We claim disability by lyric impulse. And by lyric impulse we rearrange the terms of awareness” (“Creative Writing”). By determining the “terms of awareness,” Ferris, Kuusisto
and Lambeth reclaim embodiment, by reimagining and reshaping moments from their lived experience, and from what Simi Linton calls “the vantage point of the atypical” (My Body Politic 81).

Ferris outlines what this disability consciousness means in relation to disability poetry as a genre when he observes, “Crip poetry comes from the outside, it comes from the abnormal, it is centered in the experience of being out of the ordinary” (“Crip Poetry”). A definition Ferris has given for disability poetry is “poetry that seeks to explore and validate the lived experience of moving through the world with a disability” (“Crip Poetry”). This atypical negotiation of barriers within spaces is integral to the three poets and conveys an agency and resistance to established societal and cultural constructions of embodiment. Ferris emphasises this impetus when asserting that “Fundamental to crip poetry is an understanding that disability is a made thing, a social construction” (“Crip Poetry”). He adds elsewhere that crip poetry subscribes to the social model of disability which states that disability is “caused by the way society is organised, rather than by a person’s impairment or difference, and looks at ways of removing barriers that restrict life choices for disabled people” (“On Crippling”).

Petra Kuppers also expresses how criping conventional ideas is an essential element of this genre: “To structure new tensions within given structures: that is one of the tasks of poetry. And Ferris shapes what he is given . . . of the poems in The Hospital Poems, his material is not so much found as decreed, a charting of his bodily space, his history, now in need of reclamation” (“Visiting the Hospital”). Reading the poetry of Ferris, Kuusisto and Lambeth is therefore important in determining how they individually reshape and reimagine their “history” and reclaim their reconfigured “bodily spaces,” but also in making a case for the significance of “crip contours” as a term that is more broadly applicable to modern and contemporary poetry.

Schalk describes the historical and political process of reclaiming language and the term crip: “shorthand for the word ‘cripple’ which has been (and is) used as an insult towards people
with disabilities, but which has been re-appropriated as an intra-group term of empowerment and solidarity” (“Coming to Claim Crip”). Linton’s article, “Reassigning Meaning” in Claiming Disability: Knowledge and Identity (1988) is regarded as one of the foundational essays in the field of disability studies and emphasises the expediency in reclaiming the term. Here Linton states “Cripple, gimp, and freak as used by the disability community have transgressive potential. They are personally and politically useful as a means to comment on oppression because they assert our right to name experience” (17). She adds, “Disabled is centered, and nondisabled is placed in the peripheral position in order to look at the world from the inside out, to expose the perspective and expertise that is silenced” (13).

An early proponent of crip’s social and political potential, Carrie Sandahl describes “crip” as a “fluid and ever-changing” term which “expanded to include not only those with physical impairments but those with sensory or mental impairments as well” (27). At the time of Ferris’s use of the term, Robert McRuer’s Crip Theory (2006), introduced the concept of “crip” as an identity with a different spin, similar to the umbrella term “queer.” According to McRuer, this term is “part of a global turn” in disability studies, extending beyond medical and social discussions, bringing ideas into the international sphere as a “cultural model” for art, activism, and academia (Alison Kafer 15). The verb “crip” has been variously employed as a term by disability theorists as an alternative means of critical reference in outlining modes of representation of the physical, psychological, emotional impact of medical, societal, political and cultural conceptions on ways of being in the world.

Examples of the re-appropriation of the word “cripple” in a literary context can be found in Brendan Behan’s autobiographical novel Borstal Boy (1958) and in his play The Hostage first performed in 1958 where the phrase “Every cripple has his own way of walking” is repeated (348). An early poetic example is Norman Kirk’s poem “Crip” which presents disability as a barrier, an external “surface” between the real person and the outside world (TSM 57). The title
boldly introduces the word *crip* and subsequent lines delineate its grammatical roots “. . . a noun for a name/ beyond my name. The surface that others see” emphasising the role of language in labelling others and signifying otherness (*TSM*57 8-9). Kirk’s emphasis on taking ownership of the noun highlights the complex relationship between language and knowledge systems and practices. The application of the term is complicated by the fact that some disability poets do not identify as “crip” poets and others reject the politicisation of their poetry. Thus, *crip* “is a term which has much currency in disability activism and culture but still might seem harsh to those outside those communities” (Kafer 15).

This notion of the collective community of cripples is what Kuppers refers to as “crip culture citizens,” a community of those who have “spent too much time enclosed by white, or green, or other walls” (“Visiting the Hospital”). The concept is perhaps best expressed poetically in one of Ferris’s own poems “For Crippled Things” (*STG*12). It is an example of how disability poetry utilises poetic form to celebrate atypical embodiment and uses language humorously to crip conventional viewpoints. Ferris achieves this playful effect by invoking allusions to the poem “Pied Beauty” by Gerald Manley Hopkins (*STG*12):

Glory be to God for dappled things –
For skies of couple-colour as a brinded cow;
For rose-moles all in stipple upon trout that swim (*SPGMH*24 1-3).

Opening with a hymn-like series of refrains for disabled bodies, Ferris raises a dedication to the various parts of the body that do not conform to conventional expectations of beauty in a pastiche of Hopkins’s benediction of divine creation and beauty. Cheryl Marie Wade calls it a “savage crip humor,” one through which “monstrous truths about being a crip kid at the mercy of the fix-it fanatics” emphasises the limitations of such restrictive perceptions of embodiment (“Visiting the Hospital”). Schalk comments on the way Ferris’s poetry “strikes a keen balance between an inside joke and invitation into the club of disability culture” (“Disability Poetry
Whereas Hopkins’s poem is a homage to God’s divine power, Ferris’s verse ridicules narrow minded prejudice:

Glory be to God for crippled things —
For minds as sharp as cracked concrete;
For flab that sags, for joints and thoughts that will not come unstuck;

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We are his joy, his music all we sing;
Our praise is in our flux. (STG12 1-3 13-14)

Ferris’s celebratory tone humorously rewrites or “crips” Hopkins’s “Pied Beauty” phrasing by contrasting the original notion of perfect beings with the bathetic “crippled” bodies and “cracked concrete” (STG12 2). Ferris mocks societal attitudes, reclaiming the language by parodying the original. Ferris dedicates his poem to Hopkins and includes a citation in italics directly taken from Hopkins: “Once I turned from thee and hid” (SPGMH87 9). This line originates in the hymn “Thee, God, I come from, to thee go” (SPGMH87). Whilst such “scaffolding is overt” as Northen notes, “[t]his is not literary dilettantism on Ferris’s part, quite the opposite. He is depending upon the reader's recognition of the theme of the poem he references to provide an emotional context for the one he is writing” (“Book Review: Slouching”). Ferris’s context emphasises the changeable nature of the world as a reminder that we are all subject to change.

Schalk notes that “the poetic form and language in Slouching Towards Guantanamo is also dynamic and shifting” and that “at several points, Ferris takes up the lofty diction of Christian faith, mixing the linguistic style of the Ten Commandments, the Beatitudes, hymns and prayers with the content of ‘the unfit, the twisted, the shamed’” (“Disability Poetry Power” 76 12). In “For Crippled Things,” Ferris suggests metaphorical body contours when he describes how “Our praise is in our flux” (STG12 14). This line encapsulates the wavering, ambiguous edges located at the site of what Sheila Black identifies as the body’s “unique knowledge, flux,
invention, and radical transformation” and highlights the poetic means by which abstract notions of reshaped and reclaimed non-normative embodiment are represented by poetic form and content (“Six Poets”). While these sites of “flux” can be regarded as transformative, they are often conveyed as simultaneously defensive. Ferris’s celebratory tone undermines such negativity.

Thus, crip poetry seeks to challenge “constructions of able-bodiedness and be politically generative through the fracturing of key systems of oppression” (Bone 1298). It resists held notions of body as defined by its ability to function according to pre-existing definitions of ability, independence, normativity and appearance. The action of criping disrupts this narrative as Sarah Brophy and Janice Hladki indicate: “cripping . . . entails scraping - the troubling, in the uncovering, the rupturing - of embedded knowledges that otherwise tend to sediment into uninterrogated ableist and diversity discourses” (315-316). Lambeth’s poem “Dressage, or The Attempt at Training” emphasises the body’s mutability by presenting alternative perspectives:

Further north, the journey traces
paths along my waist, midsection, settles there, the manifestation
this disease takes as it pleases, imprinting my body by stripping
away sensation and offering something else.

Or perhaps I am the horse,
this numbness squeezing my waist like a leather three-buckle girth,
like legs. Or – I can make it better: a lover’s hands there and there (VB60 14-20)

In “offering something else” the criped poem can become a platform for voices of disabled individuals to be heard and to recount the authentic narratives of lived experience, “By making room for disabled voices from all the nuances of lived experience, disability discourse can create ‘rhetorical adjacency,’ which is both ‘rhetorically positioning beside’ the disabled person while permitting disabled ‘agency’” (Bone 1308). A crip consciousness, therefore, “inverts, subverts
and re-appropriates the gaze to show the limitations of the abled-bodied viewpoint” and reclaims the shifting, reconfigured contours of embodiment (Hall 164).

When Kuppers asks herself, “What can crip culture do for poetry?” she answers: “It can turn things on a dime, open up layers of living like the petals of a rose, see our world with different eyes. It does so by not condensing difference to individual instances, but by allowing us to see our cultures as lived, as experienced, and as a shaper of the forms of people’s lives” (“Disability Culture Poetry” 13). In other words, disability poetry enables us to understand the influences that shape embodiment, to rethink our assumptions in order to resist normative definitions of identity, to reshape, “making visible the contours” of space and experience (Snyder and Mitchell “Language of Disability” 1018). Kuppers adds: “My disability links me to the contours of my terrain, to the work of finding access to trickster aesthetics, and to collaboration so I can find my way” (“Trans-ing Disability Poetry” 607). This terrain is unfixed, its contours fluid and dislocated. As Lambeth’s poem “Wrong Turn Near Pecos” states, “I don’t know where I am. /The road’s inhabitants don’t know/ what I am” (VB63 1-3). It is this process of dislocation, interaction and resistance, of slipping and reshaping the self, that disability poetics reclaims through spatial metaphors.

Ferris, Kuusisto and Lambeth all challenge narratives of normalcy by offering new viewpoints that confront prejudicial attitudes of “compulsory able bodiedness,” derogatory and discriminating perspectives which impose notions of able-bodiedness as a universalising norm (McRuer 2). The subjective representation of their physical and imagined body contours signify various states of being in space as wavering outlines fluid and in flux; sometimes as porous interior and exterior surfaces, or as containers of the psyche; at other times, representative of armouring defending against physical, psychological and emotional pain. Kuusisto’s speaker in “Emily Dickinson and the Ophthalmoscope” observes “My cocoon tightens, colors tease” and asks “What medicine for this?” (LB5 17 31). Laura Colombino outlines that “[i]n contemporary
discourse space has taken on the qualities of lived experience, an embodied practice performed at the point where the built environment and the body enter into relation with each other,” placing emphasis on the singular relational meeting point, the space at the edge of the body in proximity with societal, cultural, political practices (1).

My study of poems by Ferris, Kuusisto and Lambeth presents us with multiple rather than Colombino’s singular meeting point. I argue that these poets reconfigure the structural form and spaces of the poem in order to de-familiarise conventional able-bodied body contours. As Hillary Gravendyk observes, disability poetry asks us to “reconsider not just what kind of body a poet can use to perceive in the space of the physical, or what subject positions are normalized and excluded in the space of the social, but what kind of perceptive positions might be formed and reformed (for the reader and the poet) in the protean space of the temporarily realized poem itself” (6). These positions are subject to change, being reformed and reshaped upon contact with other people and objects. Drawing on the theory of interstitial spatiality by Victor Turner, which states that individuals are “betwixt and between” a social position or identity, I argue in the chapters that follow that embodiment involves a negotiation of a series of different, shifting “body spaces” rather than a single fixed position (27). In the poetry of Ferris, Kuusisto and Lambeth, these spaces intersect as contours that delineate, fragment and de-familiarise the body’s interior and exterior surfaces in a process which creates a distinctive disability poetics aesthetic.

Throughout this study, I also am conscious of the strong awareness of the complex relationship between poet and reader in the works of Ferris, Kuusisto and Lambeth. Their poems are, firstly, concerned with the interior self, and then turn outwards, exploring an awareness of interactions occurring through and between outside bodies and practices. The type of representation involved is described by Kobus Moolman as “far beyond a mere synergy between form and content. It points to a set of deeper relationships that traverse the inner and the outer,
the real and the imaginary, language and the body, experience and thought” (2). Thus, I propose that rather than a single line demarcating the binary of able and disabled, their poetry explores the fluctuating boundaries between the two and the ways in which different attitudes, policies and practices are manifested in spatial terms. Their diverse speakers negotiate spaces, connect with, move through and exist between, intersecting real and imagined boundaries, abstract spaces, utopian, urban and domestic microcosms, meeting at the interstices. These contours of embodiment are multiple and varied; they are asymmetrical strata that shift, alternate, enfold and fracture in unexpected and unpredictable ways. In the words of Mairs, whose quotation opens this thesis, they “swagger” in wavering lines, metaphorically inhabiting the liminal and interstitial spaces; they resist and reclaim the political and social conditions that reshape and reconstruct the concept of the self (“On Being a Cripple”). Ferris, Kuusisto and Lambeth all situate the imagined body and locate the poetic voice in the context of the environmental and spatial landscapes they inhabit.

Structure of Thesis

In order to establish the background context to the poetry of Ferris, Kuusisto and Lambeth, I first explore American disability poets who are dealing with the representation of space and whose works are deserving of further scrutiny beyond the scope of this thesis. This includes works by earlier 20th century exponents of the genre such as Larry Eigner, H.N Beckerman, Karen Fiser, and Vassar Miller. Their work lays a foundation for the significance of space in disability poetry and illustrates how it is central to questions about disability activism that challenges established notions about embodiment, especially when viewed from a crip perspective. In this way I hope to suggest that American disability poetry in general can be better understood through the lens of
space and a distinctive crip consciousness before moving on to focus specifically on the work of the three main poets.

In Chapter 1, I shift to a 21st century American disability poetry context through scrutiny of Ferris’s preoccupation with the representation of asymmetric body contours and hospital spaces as a means of resisting institutional power. His early verse *The Hospital Poems* (2004) explores bodily boundaries in the context of the institutional space of the hospital. He focuses on interstitial spaces and contours of edges, walls, corridors and boundaries to free himself from traditional, structural demarcations of time and cultural convention, enabling him to resist linear chronology and mix literary and cultural traditions. He reimagines and re-maps the boundaries of the hospital, poetic forms, and his own body.

Ferris’s *Slouching Towards Guantanamo* (2011) poetry collection develops his exploration of the disabled individual’s response to being contained and controlled by external political, societal, institutional and medical establishment powers. Northen comments:

People with disabilities are often made prisoners to the language of medical treatment which so frequently employs the vocabulary and metaphors of the military at war. We are, after all, “fighting disease.” Whether it is seeing your body or other countries as the enemy, such language creates a defensive or negative attitude in those that hold that view. (“Book Review: Slouching”)

His poems are representations of resistance; confining spatial boundaries that defined his childhood are reimagined and reclaimed through the adult speaker’s poetic voice. I show how the language of the doctors is transformed in poems like “From the Surgeons,” which Kuppers describes as the magic of “transformation through word operations, trickster words. Trenches, lines, and war waged across them. All words are part of that machinery of the line, the poetic unit that shapes new meanings” (“Visiting the Hospital”).
Chapter 2 interrogates Kuusisto’s reimagining of landscapes investigating how sight, hearing, and touch facilitate expression and communication of living with blindness. His first poetry collection, *Only Bread, Only Light* (2000), communicates a fresh understanding of a non-ocularcentric experience of the physical world, representing the negotiation of fluctuating spatial contours encountered as a blind individual. The poems chart the process of movement through space in order to explore the relationship between light and dark, shadows and brightness of light, and the navigation of objects which spontaneously appear. As a child, he often occupies the isolated confines of the domestic home, its private interiors, specifically his bedroom and the attic space. In the outside spaces, he resists acknowledgement of his blindness and hides behind a defensive veiled pretence of sightedness.

In *Eavesdropping*, Kuusisto foregrounds exterior spaces with the ear as the point of reception; he suggests that: “If you really want to hear with penetration and find its associated pleasures, you must imagine you are waking up over and over again—waking on your feet, becoming aware ‘in medias res’” (75). In the poem “Guess,” for example, his speaker’s body becomes sensitive to the music of nature itself and hears “the vibrato of recurrent wind” as it moves across fields “swept by a music/ Half-heard when rising” (*OB* 116-7). Kuusisto later expands the physical scope of his exploration, aiming to influence theoretical perceptions of blindness and reclaim control over the narrative of his perception. This is particularly evident in his second collection of poems, *Letters to Borges* (2013). Here, the different voices transgress the “terra incognita,” a term Kuusisto employs to convey the imaginative mapping of the unknown and unseen spaces on his journeys abroad. They navigate city spaces in the imaginary companionship of the literary figure Jorge Luis Borges and with the additional companionship of a guide dog. The external city spaces are reconceptualised through interior imaginative processes. In this way, his work examines both private and public spaces, the domestic and the urban.
Chapter 3 focuses on Lambeth’s poetry by looking at her documentation of the fluctuating experience of living with intermittent degenerative symptoms of multiple sclerosis (MS). Lambeth creates new spatial metaphors of the skin, foregrounding its role as a mediating surface between internal and external and offering a layered conception of the body. She articulates the subjective experience of physical and emotional pain, hidden scars and intermittent symptoms of MS in order to problematise fixed medical and cultural definitions. MS is termed a lifelong condition affecting the brain and/or spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance. It is an “unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body” (nationalmssociety.org). Lambeth’s concern is with the transference not only across and between surfaces, but between inside and outside. She expresses how she hopes her poetry can create awareness of difference by helping others to inhabit the world of her subjective experience through her poetry:

It is my hope that readers of my own work would get as close to literally feeling and inhabiting the body’s movements and sensations in my poetry and prose . . . that the poems could make the reader feel an inkling of what it’s like to live in this body and help them develop awareness of their own physicality and the subjectivity of the bodies around them. (Appendix 3 287-288)

Lambeth claims that her intention is to close the literal and figurative distance between reader and writer. I explore how her poetry strives to allow the reader to “feel” as if they are “inhabiting” the body of a real (poet) and imaginary others (the narrator).

In the final chapter, Chapter 4, I conclude with a brief commentary on possible future directions for research. I suggest ways in which further study of disability poetry might usefully add to other research areas, in particular the fields of disability studies, modern poetry, medical humanities and spatial studies. I show how the autobiographical nature of disability poetry offers
something to other areas of study: a complex and deeply personal voice; a vehicle for expression of varied viewpoints on embodiment; and a reflective reimagining of experiential realities that productively challenge normative ideas of able bodies. As Anne McGuire argues: “disability marks the body in ambiguous ways – it appears and disappears, is noticed and is hidden – as we move through different physical and social spaces, and as we find ourselves in different political and historical moments” (“Disability”). Part of the drive of disability poetry is to do with making these “marks” more visible, a need brought about by the way legislation and medical definitions sought to categorise those who “qualified” as disabled. It is necessary to uncover how such inscriptions can continue to be read and revisited.

**Background Contexts: Accessing Spaces and (Re)Claiming Disability Poets**

The writing of the three key poets of the PhD, Ferris, Kuusisto and Lambeth, builds upon the work of other writers and other disabled poets. As Clare Barker and Stuart Murray assert, “Disability is everywhere in literature” and, importantly, found “across all time periods, from the earliest expressions of European poetry to the contemporary global novel, and all points in between” (*Cambridge Companion* 1). My aim here is to establish the spatial nature of American disability poetry. Through a brief examination of the historical, literary, social, political and legislative context of the 1980s and early 1990s in which disability poetry evolved, I establish that space and productions of space are a fundamental component. An analysis of early American disability poetry helps us to understand how a more assertive documentation of disability experience emerged and is linked, I contend, to conceptions of occupying public space. It is significant, I argue, as this is the period in which American disability poetry is first defined as a genre. This section also explores how the work of the American “reclaimed” disability poets can be read, in part, as subjective and imaginative literary expressions of the cultural and societal
transformations of disability as a civil rights issue that evolved at the time of the 1990s legislation (Alice Hall 45). I say, in part, firstly because not all disability poets included in this thesis necessarily identify as disabled; indeed, some contest not only the term but the labelling of their poetry as disability poetry or like Josephine Miles, do not associate themselves with the “disability rights movement” (Susan Schweik “Josephine Miles’s Crip(t)” 50).

The development of the critical definition of disability poetry as a movement is problematic in that it raises the question of how and when we might “read disability in or into poetry” (Schweik “Josephine Miles’s Crip(t)” 48). We need to ask the question: when is a poem a disability poem? Do all poems written by disability poets inevitably have disability as their subject? Michael Davidson defines disability poetics as that which “de-familiarizes not only language but the body normalized within language” (“Missing Larry” 118). Where William Carlos Williams’s poem Paterson questions how to formulate a poetry aesthetics that can emphasise “contact” between “words, ideas, and things,” including the shape of being, disability poetry engages with representations of atypical embodiment within the physical, typographical spaces of the poem, a stylistic task which might seem equally “beyond attainment” (Alba Newmann 53). Williams’s speaker asks:

How to begin to find a shape - to begin to begin again,

turning the inside out: to find one phrase that will

lie married beside another for delight

- seems beyond attainment. (Paterson 167)

Williams seeks a uniformity of expression that unites concepts but Davidson suggests a poetry that is “jagged, partial, broken” becomes refreshed by finding new patterns and word associations (On the Outskirts of Form 280). I argue in the following chapters that the disability poetics experiments by Ferris, Kuusisto, and Lambeth explore stylistic and conceptual ways to
“find a shape” (*Paterson* 167). They experiment with forms to “begin again” disrupting by “turning the inside out” and conveying anomalous ways of moving through the world (*Paterson* 167). They use spatial imagery and spatial form to reconstruct surfaces and outlines as creative re-imaginings of moments in time, ontologically expressive of reconfigurations of the body and its relation to the world it inhabits.

The early poems of Larry Eigner, for example, foreground this emphasis on spatial relations. His poem “october 3 69 #350” highlights the negotiation of domestic spaces contrasting spaces inside the home with spaces beyond the confines of external walls and closed doors (*CT*157). Eigner juxtaposes the spatial terms of “back” and “front” with the repetition of the word “inside” in a way which de-familiarises expectations and disrupts the focus inward, turning the viewpoint inside out:

my back to the front of the house inside inside what is this sense of moving through life (*CT*157)

The concluding question, “what is this sense” is interrupted by space. The emphasis falls on the word “moving” and the displaced “through life” and the reader is left to ponder on the philosophical and metaphysical question of existing *in* and moving *through* space. There is an absence of punctuation; no strategically placed typographical mark signalling the rhetorical nature of the unanswered question. The lines extend erratically and words appear suspended. The white space gaps between “sense” and “of moving” Jake Marmer suggests, signify the speaker “searching for the word to describe the indescribable” (“Black Mountain Bar Mitzvah Poems”). He questions whether the technique is representative of the way the word “movement” might “trigger a different set of psychological, even spiritual, meanings to someone who moves in a
way that is markedly different from those around him?” (“Should Larry”). Spatially, the lines fragment and meaning disconnects yet, paradoxically, appears to move both backwards and forwards. For example, the repetition of the word “inside” projects ahead and reconnects with preceding ideas from a central point in the five line stanza. The parallel placement of “inside” emphasises how we connect with one another on the “inside” and yet remain static and separate. This pivotal layout is symbolic of the way human experiences shared by people with disabilities “cause them to be bound to and yet set apart from ‘normal’ society” (TSM Blurb).

The poetry of Ferris, Kuusisto and Lambeth, reflect these complex and ambiguous physical, metaphysical and philosophical conceptions of bodies negotiating space in order to reclaim and reconstruct understandings of disability in diverse ways. Indeed, the roots of the aesthetics of their American disability poetics can be traced back to the 1986 publication of J.L. Baird and D.S. Workman’s *Towards Solomon’s Mountain*. This collection includes poems that Ferris uses first to define the characteristics of disability poetry. Michael Northen asserts: “It would not be an exaggeration to call the publication of *Towards Solomon's Mountain*, the birth of disability poetry as a genre” (“Short History”). The title of Ferris’s second poetry collection *Slouching Towards Guantanamo* pays tribute to the first anthology of American disability poetry by emphasising their connection. *Towards Solomon's Mountain* was produced after Baird’s article “En-abled Poetry” (1983) called for a new disability poetic aesthetic; one that eschewed sentimental engagement and production of “saccharine and paternalistic poems” that made disability the “object of pity or charity” and also “rejected the image of the supercrip, the inspirational hero who overcame insurmountable odds” (Northen “Short History”). Yet despite Baird’s plea, one of the main reasons for the slow progress of disability rights according to Lambeth, “is due to ableism rooted in narratives of disability as tragedy, or narratives of overcoming, rather than forms defying narrative and claiming disability as a unique and beautiful
state of being” (Appendix 3 288). Lambeth’s observation, made several decades later, emphasises the continued need for a political agency of resistance.

All three poets address the policy reforms which set out to change attitudes and improve the condition, access and visibility of disabled individuals. The 1990 Americans with Disabilities Act (ADA), an extension of the Civil Rights Act of 1964, is credited as America’s first comprehensive civil rights law specifically designed to address the needs of people with disabilities, prohibiting discrimination in the areas of employment, public services, public accommodations and telecommunications. Yet Kuusisto’s “Planet of the Blind” blog posts indicate his dissatisfaction with progress made in changing cultural practices:

I regret having been a disabled professor. Regret follows me from room to room and there’s no help for it. I’m considered less capable, less collegial, more of a nuisance than any of my colleagues. There are too few like me in the faculty ranks to be of consequence. (“On University Constructions”)

Similarly, his blog entry expresses the need to give voice to the ways even liberal institutions are still failing to make appropriate adjustments to accommodate disability:

I will not be sad though I won’t live to see disability inclusion—full inclusion—in higher education. The road is too long, the grievous effects of false assumptions about the disabled student and scholar will take another generation to eliminate. I know this now. I imagined something different and better when the ADA was signed. I will not be sad. (“On Refusing the Sadness Industry”)

The ADA sought to open up public spaces for individuals with disabilities and legislated that “all places of public accommodation must be accessible to persons with disabilities” (“ADA Compliance and Access to Public Places and Spaces”). Whilst the act promoted awareness about accessibility in public spaces, Kuusisto’s interview comments point to the tensions between balancing legislation and aesthetics in the provision of a universal design:
I think that urban designers, architects, city planners are often so hopelessly utilitarian (what will be cheapest and serve the most standardized people?) that they miss out on the possibilities for public space. Inclusive spaces need not be expensive or ugly—I love the idea of a Kyoto of universal design. (Appendix 2 278)

Kuusisto references the Accessible Design Foundation in Japan which began in 1991 with a group called the E&C Project. Their aim is promoting accessible design (Kyoyohin) products and services to “realize a barrier-free society” (“The Mission of the ADF Japan”). Ferris voices his own concerns about notions of universal access stating how individuals as well as legislation have a responsibility for shaping future spaces: “This feels comparable to me to the people who may recognize that climate change is happening but who think that it’s really somebody else’s problem. It’s really all of our problem, and access is all our problem and opportunity as well” (Appendix 1 272). Whilst changes to access regulations provided a catalyst for reappraising architectural and public spaces, Ferris’s comments make clear that these issues continue to be of significant concern.

Nonetheless, the 1990 ADA legislation did place a renewed focus on how American society thinks about space and access which had the effect of making disability more visible, specifically, by emphasising how individuals are limited by practices and set minimum standards of accessibility and enabling marginalised individuals to have a voice. As Davidson observes, “The passage of the ADA made disability visible as public and private buildings, transportation services, and hiring practices were brought into compliance” (“Disability Poetics” 592). Indeed, by prohibiting “discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public” the act helped to make disability more visible, and this coincided with the emergence of a richly innovative disability arts movement. According to Davidson, “If people with disabilities became visible as rights-bearing individuals, they also emerged as poets and
artists who made that new visibility a subject of innovative work” (593). His comments emphasise that during this period of legislative change, poetry became an increasingly vocal medium in communicating the realities of living with a disability.

Harold Bond’s early poem “The Game” conveys how this reframing of experience can be articulated through the lens of space (TSM 25). The speaker’s reality is unseen, their true “affliction” is in not being believed. Lived reality is played out as a game of differing perception:

My affliction is
your hangup. It is yours more
than it could ever be mine.

I will not
destroy our game. At night I
dream I am Samson. I will
topple coliseums. I

will overwhelm you with my
brute power. I will knock you
dead. (TSM25-26 2-4 22-28)

The speaker re-imagines himself as the blind Samson, destroyer of temples, a symbolic figure renowned for casting out the unbelievers, creating a new space for change, and making others see reality. Bond points to the irony of the blind seeing the truth, in the oppressive nature of ableism, recast as a “hangup” of others, a “coliseum” of enslavement set to “topple” (TSM26 25). The dream is of a future where the power of words and poems “overwhelm” and “knock” the unbelievers “dead” (TSM26 28).
My argument is that this burgeoning of disability poetry is fundamentally concerned with the articulation of space, with questions of access and with what it means to inhabit public and private spaces. In addition, the focus on space I propose is characterised in the poems which evolved in the 1980s and 1990s, such as H.N Beckerman’s 1984 poem “To the Access Committee.” Beckerman’s poem provides an early example of using humour to demonstrate inequalities in the relationship between spaces, access and disability (TSM 113). The poem is formed as a letter/telegram from the “impatient” speaker, Miss Juliet to the “Access Committee” regarding her “handicapped Romeo”:

To:

The Access Committee

Attention:

Handicapped Romeo

There is now a suitable ramp

installed at my balcony.

Impatiently,

Miss Juliet (TSM113 1-7)

The poem is an example of a disabled poet “cripping literature,” that is, writing Shakespeare’s Romeo and Juliet from a disability perspective to reconfigure and satirise access issues (1595). Beckerman’s poem demonstrates how the process of criping can be a humorous and playful way of satirising societal and cultural practices. As Jay Dolmage comments, this process can “expose and reproduce disjunction, to refuse order and embrace messiness. This is at once a scabrous and fabulous process, illustrating the hypocrisy of the norm and inflating them into parody” (848-49). To use Garland-Thomson’s term, it critiques stereotypical viewpoints by reframing “normate” perspectives (Extraordinary Bodies 8).
Critical disability theorists such as Northen argue that the ADA marked a turning point in the production and reception of American disability poetry. He claims that “the passage of the ADA in 1992 seems to have been a watershed for disability poetry,” a transformative moment when a flurry of disability poetry ensued (“Short History”). He adds that while a small number of disability writing anthologies were published prior to the ADA, “it was not until the 1990s that single author books of poetry that openly confronted the issues of disability appeared” (“Short History”). This was the same point at which disability theory began to become formalised as a body of criticism. The surge in related literary composition at this time is evident from Davis’s essay, “Crips Strike Back: The Rise of Disability Studies” (1999), which is the first publication to make a case for centralising disability studies scholarship in literary studies. As Davis relates, “The exciting thing is the emergence of a whole new field in literary studies at the moment when many felt that there was nothing new under the hermeneutic sun” (510). He adds “The survival of literary studies may well belong not to the fittest, but to the lame, the halt, and the blind, who themselves may turn out to be the fittest” (510).

Subsequent disability theorists such as Carol Thomas have since made the case for defining critical disability studies as a “transdisciplinary space; breaking boundaries between disciplines, deconstructing professional/lay distinctions and decolonizing traditional medicalized views of disability with socio-cultural conceptions of disablism” (73). However welcome such critical connections and intersections have been in the field of disability studies, the place of poetry and its aesthetic role of creating, reflecting, driving, and responding to the individual lived experience has been under-explored and the specific aesthetics and politics of disability poetry are often hidden under the generic umbrella term of “disability literature.”

Ferris, Kuusisto and Lambeth all self-consciously seek to balance and intertwine the political with the aesthetic. Indeed, Kuusisto affirms the polemical in his poetics:
I always resist the medical model of disablement and to the degree my poems are polemical that would be the heart of it. Disability is rich in literal and figurative experiences and this is why so many great artists have been influenced by bodily inconveniences, Monet with his failing vision, again, Walt Whitman writing after his strokes, Jackson Pollock’s clinical depression—disability is everywhere in art once you learn to look for it. (Appendix 2 275)

Kuusisto highlights here the merging of the political and aesthetic, and poetry’s capacity to draw attention to different cultural conceptions of beauty.

This thesis seeks to explore and challenge the idea that poetry can be both a reflection of and a device responsible for driving social change. I argue that the “political potency” of poetry, as Michael Dowdy terms it, retains much of its power more than thirty years after the ADA legislation as poets continue to navigate ways of reconfiguring and reclaiming representations of lived experience. Dowdy adds, “Poetry is political . . . when it ‘keeps in touch’ with experience” adding the reminder that the speaker-poet’s experiences are “part of a larger collective experience” (35). I contend that much disability poetry engages with questions about space raised by the legal Act and its attempt to define disability and acknowledge the rights of individuals by making changes in access a legal requirement.

In a similar vein, Lambeth articulates how she believes that her own poetry helps to make the case for society to be made more accessible for all and expresses this in a way which makes clear how poetry does not merely reflect the culture of its production, but has the potential to influence the attitudes and lived realities of its readership:

I would like to help society perceive disability and difference as beautiful . . . I mention, “having some perceptual walls broken down [. . .] helped me become more aware of the body's variability and oddness.” I hope that those walls can be broken down for readers, so that they understand—whether they are temporarily able-bodied or disabled—that
physical certainty is a myth, and that they, too, exist in a variable sense of time and ability, a fact that could be accepted and celebrated, rather than feared and cured. (Appendix 3 281)

The temporality of embodiment emphasises that reality is always shifting. This concept is pertinent given that Lambeth was not born disabled. MS changed her perception of her sense of self. Kenny Fries makes a similar point, “In many ways, all of our futures are tied to the future of disability. The bottom line is that a large percentage of us will be disabled, if we haven’t already been, for short or long periods. As we age, most of us will become, in some way or another, disabled” (“How We Think”). Lambeth also cautions:

This mind-frame might not immediately make society more accessible, but it could help people understand that access for disabled people means access for themselves at any time, and that the barrier between disability and what is considered the norm is elastic and potentially broken, which is okay, just a new way of dwelling in the world. And if the world is more accessible and open to the multiple modes of accessibility, then that new way of dwelling in the world will feel more natural for everyone. (Appendix 3 281-282)

In order to achieve a metaphysical and metaphorical dismantling of walls which contain and constrict, Lambeth’s poetry uses spatial metaphors and experiments with typographical spacing and structural form to create a distinctive disability poetics.

Lambeth’s conceptual approach has similarities with Fiser’s poem “Pointing to the Place of the Pain,” which asks us to imagine the body in geographical and architectural terms (WLFP12). The spatial metaphor of a public “region” references a space that is distinct from another area (WLFP12 10). Region stems from the Latin “regionem” which means a direction, boundary, or district. It is juxtaposed with the interior “room,” a space enclosed within four walls to which entry is possible only by a door that both connects it and separates it from other similar rooms (WLFP12 13):
Imagine the pain you inhabit as a region
In between, ineluctably your own
Like your softest skin or the space of freedom
Where your memories happen, a room
No one else can come into,
However close they try to stand. (WLFP12 10-15).

On this occasion, the speaker asks the reader to imagine, to visualise chronic pain as an embodied space. But the inhabited space is liminal, existing in the interstitial “region/ In between” (WLFP12 10-11). This interconnecting space is “ineluctably your own” and unoccupied by others. The phrase reflects the singularity of the experience of pain whilst yet connecting with others who also experience pain. In this private space of memories, accessible only to the owner of that pain, the “you” as reader is required to reconsider the epistemological problem of ascribing and knowing someone else’s pain (WLFP12 10). Lambeth elucidates the feeling of separateness in the following terms, “You’re just a walking, standing question. This brings us back to what compels me about Wittgenstein and Scarry: people outside a disabled person’s body and mind will always approach the disability or pain with doubt, because they do not feel it” (Appendix 3 279-280).

Ludwig Wittgenstein sought to explore the problem of communicating pain through an analogy of a toothache in his work *The Blue Book* (1934). He argued that to refashion understanding of the pain of others is to rethink the clinical and social practices that normally consider pain as an incommunicable experience. He points out semantic ambiguities regarding grammatical expressions of the knowledge of the sameness of someone’s pain for example, stating “If only you can have real toothache, there is no sense in saying ‘Only I can have real toothache.’ Either you don’t need ‘I’ or you don’t need ‘real’” (*Philosophy and Illusion* 68). Fiser’s speaker is isolated, feeling their own pain, in a “space of freedom” an interior “room” inhabited in order to protect the sense of self from pain and the gaze of others.
For Kuppers, poetry provides this space, combining a dual function of agency and therapeutic healing, when stating that a “sophisticated companionship, can open spaces of agency, and can allow connection in anger as well as in healing” (“Visiting” 106). This concept of poems as rooms is similarly expressed by Lambeth:

The concept of a poem being space, or the page being space, is so interesting, not only because a stanza is a room in Italian, but because a poem houses movement, sound, and speed, too. It’s a moving space with associational turns of mind, memory, image, and feeling, with the potential for new associations leaping between lines and across gutters.

(Appendix 3 284)

Poetry’s capacity to condense space and make complex, unexpected connections enables writers to express criticism regarding the slow pace of legislative reform which fails to represent the validity of the disabled body, the primacy of disabled experience, and give visibility to the hidden.

Regulation of public spaces is not a new phenomenon but has been an important aspect of governing and defining disability experience across American history. From the 1860s to 1974, the so-called “Ugly Laws,” sought to control who could be visible in public space. Schweik argues that the ugly laws were used to “repress the visibility of human diversity in social contexts associated with disability and poverty” designed to limit the access of “unsightly” persons, defined as “any person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object” from public spaces (“Kicked” 1). “Id. at 21” is a poem from Arthur Honeyman’s collection, Umbly Yours (1992). Reprinted in Schweik’s article “Kicked to the Curb: Ugly Law Then and Now,” the poem has the speaker address the “troublesome sidewalk - blockers of Portland’s Management Plan,” the unsightly beggars whose public presence, disrupts the pavement space (15). The poem’s theme becomes a wider social satire reflecting society’s apprehension regarding the presence of individuals in public spaces who are viewed as non-normative and undesirable. “Id. at 21” links disability to other identity issues of “class conflict,
class privilege, street violence, ableism, communication impairment” through the imagined interaction between homeless and disabled and the conflict between both groups to access public spaces (“Kicked to the Curb” 15). It alters from the subject matter of liberal reform to more atavistic, ancient ideas of cripples and beggars and proves that a “simple sentimental alliance” between marginalised groups may remain elusive (“Kicked to the Curb” 15):

i do not trust you
because I am lucky
in my circumstances
and do not now
have to pan handle
i would like to
give you the coin
that you have asked for
but experience teaches me
that beggars often abuse
charitable minded cripples
like me by conning us
into allowing them to go
through our pockets or purses
then rip us off and leave us
feeling like the foolish idiots
that most of even our modern society
perceives us to be
and in all candor
it is far too high a price to pay
and therefore
brother or sister whoever you are
i smile at you and rapidly pass you by
uttering these words of a good friend
i hope your situation improves dramatically ("Id. at 21" 1-25).

Honeyman sets the scene on the city streets where a beggar is addressed by the speaker who gives a “smile” but moves “rapidly” away avoiding further interaction (“Id. at 21” 23). The chance meeting, however, serves to emphasise the similarities of their treatment by the wider community. The commonality of experience is emphasised by the fact the speaker does not “now/ have to panhandle” implying they too had been shamed by a “modern society” that perceives “cripples” as scroungers and “foolish idiots” ("Id. at 21” 5 16-17). In fact, Honeyman was refused service in a Portland pancake house in 1974 and got arrested for refusing to leave. In other words, he was detained because of not keeping the “ugliness” of his disability hidden from public view. “Id. at 21” reflects on the politics of representation in public and city spaces.

Honeyman’s poem, Schweik writes, makes clear that “it matters not only that we see others but where we see other: persons, or disability, relegated only to the verge or the gutter or the curb are in no position to articulate demands” (“Kicked to the Curb” 16).

Honeyman’s “Id. at 21” also parodies the complexity of issues arising under the ADA legislative reforms and the numerous guidelines issued between 1993 and 1999 which provided additional interpretations on “pre-employment inquiries and medical examinations, workers’ compensation benefits, psychiatric conditions, the meaning of the term ‘qualified,’ and the requirement that employers provide ‘reasonable accommodations’” (“The Americans With Disabilities Act of 1990”). “Id. at 21” points to the failure of “our modern society” positively to discriminate and accommodate disability even amongst the most vulnerable; it highlights the narrow minded prejudice within society that “perceives us to be” better ignored, passed by as if
invisible (“Kicked to the Curb” 18). It mocks comments asserting that “As a result of recent political action by the ‘invisible’ minority of Americans with disabilities, these citizens can now enjoy equal educational opportunities, access to public buildings and services, and fuller social participation” (TSM Blurb).

Kuppers observes that the dynamic interaction of crip culture and crip poetry expands the different spaces *where* we see other and “opens up layers of living” thereby enabling others to “see our world with different eyes” (“Disability Culture Poetry”). Yet Lambeth cautions against expecting all readers to achieve this transformation when she comments:

> I have heard from some readers, though, a distancing objectification of the speaker in my poetry, the reader unable to cross the line of gender or physical ability to inhabit something different. (Appendix 3 288)

Nevertheless, Lambeth’s observations on the methods she employs relate the importance of emphasising the spaces of the body in disability poetry: “. . . what I hope for: a sense that the poems could make the reader feel an inkling of what it’s like to live in this body and help them develop awareness of their own physicality and the subjectivity of the bodies around them” (Appendix 3 288). Lambeth’s aspiration to situate her body in the space of the poem expresses a phenomenon that early disability poets are recognised for helping to bring about.

Northen cites two other important early collections that led to a poesis of embodiment inspired by human rights, *Despite This Flesh* (1985) edited by Vassar Miller, and *With Wings* (1987) by Marsha Saxton and Florence Howe. These texts are significant, Northen states, because Miller’s approach indicates how she, like other disabled poets, had previously “kept her own disability out of her poems” (“Short History”). In *Despite This Flesh* (1985), Miller’s first collection that engages with her own autobiographical experience, there is a striking focus on ways in which the body negotiates interior architectural spaces. For example, in “Visit to the
Institute for the Blind,” she interrogates what occurs when sight is redundant as the dominant sensory mechanism for navigating space (*DTF* 52):

All objects have evaporated here, turned into sounds and echoes. Walls are white vibrations nesting on fingertips, doors are brown currents of space. (*DTF* 52 13-16).

The architectural spaces of the Institute are not marked by objects that can be read by the eye; rather, the walls and surfaces vibrate. These reconfigured spaces are “turned into/ Sounds and echoes” and transformed as soundscapes, designated by moving “currents” rippling and coming to rest (*DTF*52 14). The space itself is not just a metaphor but a setting that the individual fully engages with, primarily through touch. Rather than the eye acting as the receiver of environmental knowledge of the physical location, the fingertips are the point of reception. The walls vibrate as if moving and then settling “on” the skin surface (*DTF*52 15). This blurs the delineation between the architectural spaces and the body of the speaker and gives her a unique experience of interconnected soundscapes, colours and memories. In spaces contained by customs and institutional power, objects dissolve, become “evaporated” and transformed (*DTF*52 13).

Kuusisto similarly sets out to blur the liminal space between sight, touch and sound. He affirms that the medium of lyric poetry with its flexible language and form, effectively communicates his own awareness of physical, institutional and societal boundaries:

But the lyric insists there is life outside the hospital - life beyond the ward. Notice that lyric poetry concerns itself with containment. One can add adjectives that work well with suppression: abject containment, unaware containment, irrational containment – disability studies scholars will recognize this impressionistic terrain as inherently akin to the historic figurative language of disability–the lyric concerns itself with the conditions of individual
abjection and is always therefore a fit medium for exploring disability awareness.

(“Creative Writing”)

The versatile lyric disturbs ingrained patterns of meaning which we each attach to our unique experience of language. As Elizabeth Talerman relates: “We internalize language and interpret it based on our own experiences, from the past or the present . . . Kick off the wrong emotion and all intended meaning may be lost” (Kenny Fries “How Everyday Language”). Kuusisto’s emphasis on the transformative function of the “language of disability” can also be found in some of the work of reclaimed poets. Fiser’s early collection, *Words Like Fate and Pain* (1992) contains poems such as “Wheelchairs That Kneel Down Like Elephants” which chronicle the experience of living with a disability in intimate and often highly personal ways, formulating a language and voice in order to reclaim control over her own experience (*WLFP5*). It makes direct reference to making bodies visible by describing the speaker’s pain and the problem of accessing space as a wheelchair user:

> Last night I rode a tightrope
> with my wheelchair. No net.
> The night before, I left my body
> on the steep ground with its pain. (*WLFP5* 1-4)

The verse articulates the physical and emotional dissatisfaction experienced when completing simple commonplace acts like entering buildings or going up stairs. These repeated frustrations with access issues are veiled by a safety “net,” a defensive outer facade that projects a false face continually “smiling, smiling” (*WLFP5* 2 11). The protective barrier is not needed at night and is left behind. During the darkness of “night” the speaker “invents,” fashioning imaginative spaces in their mind (*WLFP5* 12). She imagines spaces outside of herself, finding a “new means of locomotion” new ways of accessing the buildings (*WLFP5* 12). The spaces are “Intricate/ engines
of need and night and air” and are given breath and life on the page (WLFP5 16-17). The poem invites us to question our assumptions about the proper relationship of public and private.

In reading published poems, we enter private spaces of pain and rupture exposed to public scrutiny. As readers, we access these spaces and yet may remain strangers to the particular subjective experiences they depict. However, Ferris cautions against the expectation that all disabled poets seek exposure or regard connecting with others as automatically empowering: “Disability culture, which values interdependence over the illusion of independence, privileges not a uniform perspective but the validity and value of a wide range of ways of moving through the world - and the varied perspectives those different experiences engender” (“Keeping the Knives Sharp” 91). Some poets also write of the struggle to expose themselves to the gaze of others. Analysis of imagery, for example, in “from Testaments” by James Weigel, Jr., provides an early example of a poem where the body is re-imagined with an outer covering to protect the self (TSM 13). Weigel presents a metaphor of containment, of the body as a glove, a man-made garment covering the surface of the interior self. The process of uncovering by removing the glove, exposes the spaces inhabited where disability gives the speaker their sense of identity:

I would slip
this glove of body off —
humped, bony, sweated, sore —
except the weary thing
shows where I live. (TSM14 40-44)

The outer gloved body protects, yet the word choice “slip” indicates a vulnerability, an idea of something unintentionally or too easily lost (TSM14 40). A glove is a sheath of fabric that guards the skin against the touch of other objects and makes invisible the true nature of the interior body. The gloved body is presented as “weary” of the struggle, preferring to keep the bony skeleton on the outside to protect the interior of his imaginative mental spaces (TSM 14 43). In
Bond’s poem “The Game,” the item of clothing is a coat: “You put my/ coat on for me when I
ask/ you. You put my coat on for/ me when I do not ask you” (TSM 25 7-10). It is a motif
signifying the struggle for agency. The covering and uncovering of the body can be read as a
metaphor of concealment and exposure; a way of representing the duality of a protected and yet
vulnerable embodiment.

Indeed, the overall sense in Weigel and Bond’s poems is one of isolation and of an
identity seeking to avoid exposure. This articulates a key tension that extends throughout much
of the disability poetry explored in this thesis, between invisibility and hyper-visibility. Weigel
captures these concerns when drawing attention to the specifics of the glove protecting the
speaker’s particular cultural location. In identifying the place “where I live” the removal of the
glove would reveal what is presently hidden: his sense of belonging. Ahmed’s work on the
concept of the “stranger” emphasises embodiment as constituting a series of interpersonal and
societal practices and relations, encounters which engage with the reading of “the bodies of
others we come to face” (Strange Encounters 20). For Ahmed, these encounters between
embodied others “involve spatial negotiations with those who are already recognised as either
familiar or strange” determining whether an individual is perceived as “out of place” or not
belonging in a space which can lead to stigma (24).

Weigel’s poem communicates complex feelings of belonging, invisibility and exposure
that can be linked thematically to reflections on government attempts to define who qualifies as
disabled. Ensuing debates on disability and impairment highlight that the relationship between
disability and illness was a deeply problematic one in this period. As Susan Wendell points out,

Many people are disabled by chronic and/or life-threatening illnesses, and many people
with disabilities not caused by illness have chronic health problems as consequences of
their disabilities; but modern movements for the rights of people with disabilities have
fought the identification of disability with illness (“Unhealthy Disabled” 17).
Even when adjustments to the language of legislation occur, Lambeth comments on how judgement of external appearances remains an issue:

In essence, I often pass. Living with an invisible disability, or multiple invisible disabilities emanating from one disease, can make me an object of suspicion, that somehow I am trying to benefit from accessible parking, or an accessible toilet, or that somehow I am lying, and it can also render me a curiosity. (Appendix 3 279)

The fact that some impairments are static, others episodic, some degenerative and others terminal is a key concern for those whose symptoms like MS are intermittent and invisible.

By contrast, Fiser’s poem “Pain as Metaphor” from her collection Losing and Finding (2003), depicts the body surfaces as physically and symbolically marked by pain, using imagery which highlights how stigmatization can be linked to a history of branding the skin in ways that are permanent (LF20):

Surely it is inscribed in me by now,
written deeply in the soft bare skin.

I am scarified by pain, incised forever,
as in Kafka’s story. My heart is
engraved with terrible propositions.

I think I am read in the street
like the Tattooed lady. My body
wears the much too much of it,
public and exorbitant, my face

is a map of the neighbourhood of pain. (LF20 1-10)

The body’s interior and the exposure of invisible surfaces, is emphasised through the repetition of “in” rather than on and given a hidden presence in the subtle use of “inscribed” and “incised” (my italics) (LF20 1-3). The interiority of pain as a sensation paradoxically “scarifies” the skin
and cuts “deeply” into the body as if giving a visible presence on the outer surface of the skin (LF20 3). Garland-Thomson outlines what can occur when a body becomes more visible but is marked as a stranger: “Stigmatizing is a social process that hurdles a body from the safe shadows of ordinariness into the bull’s-eye of judgement. As appearance became standardized in the modern world, particularity came to be understood as aberration rather than simple variation or distinctiveness” (Staring: How We Look 45). In Fiser’s poem, these moments of experience of stigma mark the body: the skin wears the story like a tattoo, metaphorically scarring the flesh, making private experience visible, exposing the “map” of the personal journey as a palimpsest surface to be read by passing strangers (LF20 10). Pain is worn like a garment, the skin dressed in an inked narrative. The poem’s message is made clear: the personal psychological cost of exposure in “public” encounters with societal and cultural attitudes and practices is “exorbitant” and interior experiences are made visible on the outer surfaces (LF20 9).

The metaphorical representation of invisible forces in contact with or rupturing and exposing the interiors of the non-normative body is a motif used to link ideas of resistance to systems of social oppression. Thomas, for example, 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 wellbeing” (73). But how do poets re-imagine interior, invisible, somatic experiences of illness and chronic pain or the impact of “social oppression”? The poem “Institutions” from Josephine Miles’s collection Coming to Terms (1983), centres on her experiences of illness, recovery and the fear of the oppressive institutional power of the school and hospital (CT37):

At term end the institution slackens
And I have done poorly, not what I hoped.
So my thought is seized by other institutions
More terrible, where I would do less well.
Hospital, asylum, prison, prison camp,
And I fall into a reverie of dismay:
Failure to aid survival, failure to foster,
Failure to understand how the oppressions start (CT37 1-8).

Thoughts are “seized” by fears of past and future failures; these fears multiply and reinforce a sense of a lack of individual agency. The notion of being confined by internalised rules and regulations is suggested through the references to “asylum,” “prison” and connotations of Nazi genocide in the term “prison camp” (CT37 5). A Foucauldian loss of freedom is alluded to in these sites of institutional power where unseen “oppressions start” (CT37 8). The cumulative repetition of the word “failure” emphasises a growing recognition of powerlessness (CT37 7). Frustration with the perceived failure to overcome boundaries of oppression is replicated in the fixity of the repeated phrasing. According to Robert Gleckner, Miles’s repetition and reformulation of a “number of small recurring selections and arrangements working together” is a deliberate poetic process in “creating and reshaping expectations” (133).

Alongside the political and the legislative, this thesis makes the case for disability poetry as a celebration of beauty, creativity, and aesthetic experimentation. In his chapter on “Disability Poetics” (2012), Davidson states: “disability poetics does not describe a movement or an aesthetic so much as a spectrum of positions around embodiment - from poets like Eigner who seldom referred to his neurological condition to self-consciously “crip” poets for whom poetry is an arm (or leg) of the disability rights movement” (598). Tom Hibbard, for example, equates the particularity of Larry Eigner’s cerebral palsy to a “limited or confined” experience replicated in his “to some degree literal” expression of embodiment, saying “[i]n the context of Eigner, the idea of factuality and the experience of it are specifically linked to limited mobility” which is then “underscored and embodied in the life and poetry of Eigner” (5). Gravendyk notes,
however, that “Eigner makes use of textual space neither as compensation for his limited mobility nor as a mode through which to transcribe his own body” (11).

In the brief overview above, I have introduced some of the ways in which disability poetry uses space to explore notions of invisibility, visibility and hypervisibility, drawing on legislative history and experiences of embodiment. My thesis counters readings that understand disability in isolation, and instead offers readings of the selected disability poetry as expansive and dynamic expressions of how we need to think about all bodies, whilst preserving the subjectivity of the individual poets. In presenting disabled embodiment in the context of many different spaces, this project seeks to demonstrate how through poetry, “disabled people have celebrated difference and rejected the ideology of normality,” resisting depictions in which disabled people are devalued as “abnormal” and deviant (Swain and French 577).
Chapter 1: Institutional, Imagined and Transformative Spaces in the Poetry of Jim Ferris

Introduction: “I’m sorry - this space is reserved”

I’m sorry – this space is reserved
for poems with disabilities. I know
it’s one of the best spaces in the book,
but the Poems with Disabilities Act
requires us to make all reasonable
accommodations for poems that aren’t
normal. (“Poems with Disabilities” STG1 1-7)

This chapter explores American disability poet Jim Ferris’s poetry, life writing, articles and conversations with me and others in the disabled community. His poems articulate ideas about selfhood and explore disabled patient identity in 1960s America from a retrospective twenty-first century perspective. The lived reality of institutional space in hospitals is depicted from a child’s perspective and synthesised by the subjective adult narrator in the poems, whose imagination serves as an outside interpreter of historical events. In later poems, Ferris turns his focus outwards, re-imagining an idealised nation structured around equality and justice. While the majority of poems analysed in this chapter are from Ferris’s The Hospital Poems (2004) (HP), some other key examples including “Slouching Towards Guantanamo,” “Continental Margin,” “Poems with Disabilities,” “Medical Imaging” and “Manifest Destiny” are from his later collection Slouching Towards Guantanamo (2011). His acclaimed “The Enjambed Body: A Step Toward a Crippled Poetics” (2004) and “Crip Poetry, Or How I Learned To Love The Limp” (2007) are celebrated essays in the field of disability studies writing which engage with disability and poetry from a socio-cultural perspective. Kaite O’Reilly states that Ferris’s work is “almost synonymous with disability poetry” (“In praise of disability poet Jim Ferris”). She notes, “His first book, The
*Hospital Poems*, was one of the first books of poetry to be used in disability studies programs in colleges” (“In praise of disability poet Jim Ferris”). As an academic, Ferris explores embodiment to contest established thinking about the potential of disabled individuals. Kathi Wolfe describes his debut collection as a “sharper instrument of social change than any political revolution” (“The Hospital Poems”). According to Wolfe, much of his “trenchant, defiant, and poignant” verse communicates lived experience to contest “the tyranny” of the “normal” (“The Hospital Poems”).

Ferris’s poems scrutinise spatial dialectics of “tyranny,” crippling values and practices that are a reflection of societal and organisational distributions of power (Wolfe “The Hospital Poems”). His poems are not a straightforward “exposé of oppression” such as the discrimination narratives outlined by Mitchell and Snyder (“Low-Level Agency: Disability, Oppression and Alternative Genres of the Human”). Instead, Ferris examines the complexities of what it means to be a voice for disabled people, creating poetry that highlights the communal interdependency of being with others and celebrates “lived experience of moving through the world with a disability” (“Crip Poetry, Or How I Learned To Love The Limp”). Ferris suggests that poetry can “make the world in which we live roomier, not only more transparent and known, but to make more space in the imagination, and so in the culture, for the wide and startling variety of rich and fulfilling ways that real people live and love, work and play in this world” (“Crip Poetry”). Ferris’s narrators are situated in the marginalised and contained spaces of the hospital, its specialist rooms, corridors and beds. In later poems, they are figured located at the edges, on the periphery of liminal borders between “real” and “imagined” worlds.

Ferris invites readers to consider embodiment from a disability perspective by emphasising that knowledge does not come from external appearances. Paradoxically, disability perspectives communicate lived reality from the outside looking inward as an expression of a seeing/being seen dyad. Ferris explains this dichotomy commenting on how “crip poetry comes from the outside: it comes from the abnormal, it is centred in the experience of being out of the ordinary.” He
expresses his attempts to situate his discourse of embodiment at the edges of existing narratives, juxtaposing the thesis of the ordinary with its antithesis of abnormal (“Crip Poetry”). He explores ways poetry can influence thinking, representing difference and alternative realities of lived experience without exerting the control that other forms of language instil:

As a maker in the process of poiesis, I don’t get to dictate, but I do get to suggest, to influence – and I always want to leave space for, to ask (and demand) that readers and auditors bring something of themselves to the transaction. That seems to be an important form of restraint: I want to leave room for each reader and listener to complete the sentence, to bring their own thoughts and feelings and memories – their own colors – to the mix. (Nicelle Davis)

Ferris describes what he sees as an inherent tension in language, looking at the difference between words which have the power to manipulate and those which initiate ideas. The language of “restraint” which inhibits the growth of ideas is juxtaposed with language that promotes variety and gives “room” to expand (Davis). He is also highly attuned to the question of the agency of the writer who, he argues, must guard against creating stigma by exerting control over their own words. His poems crip cultural regulations and rituals that limit language and ideas through habit, custom and law. Writing disability has, Ferris suggests, its own dangers, as does using language to categorise and define different kinds of embodiment. Kuppers notes:

So if we acknowledge that power, we need (sic) also address the sway our larger words, our myth-fragments, can hold over our bodily imaginations. As a writerly reader of poetry, I want to reclaim the whimpering ‘cripple,’ and let it move, rather than stand like a forceful crip.” (“Disability Culture Poetry”)

His poetry creates a space for the public expression of disabled embodiment in a highly visible, audible form. For example, the poem “Poems with Disabilities” mocks the legislative powers of the ADA Act (1992), referencing an alternative “Poems with Disabilities Act” in the opening
stanza (STG 1 2). It crips the legislative language of “reasonable accommodations” insisting on reserving a space for disability poetry (STG 1 5). It makes the point that poetry has the capacity to expose inadequacies of societal policies and legislation by putting the body at the centre and poetry at the edges of resistance:

There is a nice space just
a few pages over – in fact (don’t
tell anyone) I think it’s better
than this one, I myself prefer it.
Actually I don’t see any of those
poems right now myself, but you never know
when one might show up, so we have to keep
this space open. (STG 1 7-14)

Ferris’s poems, I contend, move beyond the politics of the personal, speaking to present day issues, keeping the space “open” and giving voice to matters affecting members of the wider disabled community (STG 1 14). Opening space, therefore, is about more than changing physical environmental barriers; it is about opening up one’s mindset, reclaiming language and eradicating social and medical stigma.

Born with a physical mobility disability, Ferris spent much of his childhood and adolescence in hospital, hyper-aware of the asymmetric outline of his body form. At this stage of his life, he was prevented from accessing spaces, partly because corrective surgery meant he could not physically move. As a poet, Ferris delights in challenging the reader to take note of the narrator’s outer form through the content and form of his poems. Whilst Lambeth’s poems illustrate how the invisible nature of MS exposes the speaker to ridicule, Ferris’s narrator in “Poems with Disabilities” ridicules those who make assumptions based on outward appearances.
The decreasing line length is a highly visual representation of the asymmetrical contours of his own body:

You can’t always tell
just from looking at them, either. Sometimes
they’ll look just like a regular poem
when they roll in... you’re reading along
and suddenly everything
changes, the world tilts
a little, angle of vision
jumps, your entrails aren’t
where you left them. (STG1 14-22)

In “Poems with Disabilities” Ferris does not elect to “pass” for able-bodied in the manner that Kuusisto does in childhood, instead, he invites us to stare. The statement: “You can’t always tell/just from looking at them, either” is addressed directly to the reader (STG1 14-15). The colloquial direct address of “you” is repeated a further five times; this has the effect of challenging and engaging readers in an active encounter. Brenda Brueggemann emphasises the complex and contested question of what it means to have an invisible or visible disability:

This is the paradox of visibility, another of disability culture's great concerns: now you see us; now you don't. Many of us ‘pass’ for able-bodied - we appear before you unclearly marked, fuzzily apparent, our disabilities not hanging out all over the place. We are sitting next to you. No, we are you. (369)

The tapering verse reduces the sentence to a single word and encapsulates the sense in which “If we all live long enough, we’ll all be disabled” (Brueggemann 369).

Ferris’s poetry, I argue, sets out to shift paradigms that limit what we know by what we see and, importantly, what we write down. He does this by representing and approaching space
in new ways in which Ferris uses imagery that “tilts” and changes our “angle of vision” (STG1 14-22). Crippling the perspective highlights how disabled individuals’ lives are governed by contact with those who organise or conceive the values of the space. Ferris re-conceptualises real spaces to emphasise the disparity between intention and lived reality. In his later poems, words are reclaimed from the Constitution, the statements and declarations of the Founding Fathers to create a melange of voices and ideals. Familiar citations are fragmented disrupting expectations and “suddenly everything/ Changes” to create new meaning (STG1 18-19). In doing so, Ferris’s poetry has the potential to inform, challenge and change future thinking in unique ways.

At a fundamental level, his poems unsettle conventional notions of ableism, replacing them with numerous variations of embodiment that expand assumptions and framings of disability. They represent transient moments of lived experience in dynamic ways that keep us open to the possibilities of new meaning. Alice Wong argues “We gotta make people uncomfortable . . . And we have to challenge our praxis, the way we do things and think about things” (Carrie “Resistance and Hope”). Ferris states that poetry can make the world more accessible, make us reflect on ways “to open the world, to pay attention to what is, without getting stuck there” (“Disability and Poetry” 273). His poems are a part of what he sees more broadly as a reflective art form which challenges how we see ourselves and others. As Davidson notes “A disability poetics, while forged within the liberating ethos of the Independent Living movement, creates a site where the putative normalcy of bodies, sensations and agency can be understood differently. If this has been poetry’s ancient heritage, it is also disability’s utopian horizon” (“Disability Poetics” 598). The gap between the reality of lived experiences and the prescriptive ideals of normalised embodiment is represented through images of detachment, exposure and marginalisation in Ferris’s poetry:

I do think we’ve made some progress, but there is so much more that is needed. Maybe this is the heart of the problem: nondisabled people don’t recognize that disabled people
are the most creative people on the planet, because we have to be . . . creative and
determined and imaginative and help each other out, and then do it again tomorrow,
because we live in an ableist world that isn’t even perceptive and imaginative enough to
recognize the huge contributions disabled people make just by living every day.
(Appendix 1 268)

This chapter examines this rich intersection between accessibility, ethics and equality in Ferris’s
poetry through a focus on representations of physical spaces and spatial thinking. Literal and
metaphorical notions of containment feature in The Hospital Poems, represented by the wards,
windows and waiting rooms of the hospital. The specialist rooms are depicted as very distinct
physical memories but they also function as metaphorical representations of cultural and
institutional spaces that regulate, contain and control. On one level, these prison-like spaces
represent microcosms of societal values; they signify the “rituals of devaluation and degradation
that take place within so many spaces within our society at large” (Carrie “Resistance and
Hope”). The emphasis on these spaces in Ferris’s poetry also highlights the sense in which the
experience of disability is centred on the relational contours, contacts and connections between
individuals and the spaces they reside in. Ellis Finkelstein describes how certain institutions such
as monasteries, mental hospitals and prisons “so emotionally overwhelm their residents that they
lose their identities” (67).

During his childhood and adolescence, Ferris underwent numerous surgical procedures
which failed significantly to alter his outward shape, leaving him mentally and physically
scarred. In his semi-autobiographical poetry, he represents the disconnection between the
persona’s interior psyche and the external setting, focusing on the hospital encounter as one that
is experienced as a kind of exposure or containment. According to Madeline Karmel, the
“barriers that the institution places between the “inmate” such as the patient and the “outside
world” mean that they are “dispossessed of certain roles” that embody sense of self (134). In
Ferris’s writing, this experience of detachment is represented through motifs of clothes and plaster casts which cover, constrict and reconfigure external surfaces of the body.

The first section of this chapter, “Hospital Space and Architectural Structures of Containment,” explores the relationship between space, power and disability identity in three poems in detail: “Coliseum,” “Child of No One” and “Exercise of Power.” Ferris explores the institutional power of the hospital through his representation of enclosed treatment rooms, hospital beds and corridors. These metaphors of architectural spaces also serve as powerful metaphors about power, societal repression, and cultural practices and medicinal routines that erode the speaker’s sense of self. In the poem “Mercy,” for example, Ferris crps notions of authority by complicating the designated ownership of public and private spaces. He highlights the ambiguity of being included and excluded by those who invisibly govern the space. Hospitals typically limit the proximity of outside others such as parents by restricting visiting times and access to wards. However, “Mercy” inverts these expectations, announcing that visitors are unwelcome strangers, “aliens” refused entry to the private space of the patient’s “world”:

How did these aliens get in? How can they breathe

in here? This world is not open to you –

leave now, trespasser, you who seek to gaze

on my humiliation. (HP18 2-5)

Ferris crps societal attitudes and medical practices that set out to cure the “strange” (HP18 3). Medical treatments and routines remove personal barriers of protection and expose the narrator to the “gaze” of others (HP18 7). The exposure of outer surfaces leaves the narrator emotionally “naked” and “humiliated” (HP18 3-8). Erving Goffman suggests that institutional spaces such as asylums expose the vulnerable interior psyches of their inhabitions through processes of humiliation and “mortification” (Asylums: Essays on the Social Situation 24). The procedures strip away personal possessions and the narrator’s sense of self. Karmel observes that loss which
involves a “curtailment of the self” produces “feelings of humiliation and an accompanying loss in self-esteem” (134). The abrupt single word sentences in Ferris’s “Mercy,” including “Stuck.” and “Dumbstruck.” highlight how medical interventions cause great psychological damage (HP18 4). Paul Longmore echoes this sense of damage in his own reminiscence of hospital stays in the same period: “The course of corrective treatments utterly failed to meet its medical goals, let alone its social ones . . . the most well-intentioned of medical treatments pathologized their very being” (xvii).

The stultifying nature of the hospital space is also conveyed through the motif of clothing in Ferris’s poem “Mercy.” The “clothes, casts, chariots, carts” that reshape the body’s outer contour become the focal point of deep-rooted fears in the alterity of the other (HP19 25 26). According to Murray, these are the fears that “disability disturbs . . . as an anomalous and deviant version of humanity that nevertheless focuses all too uncomfortably for many on the central issues of the human condition” (“Bartleby, Preference, Pleasure and Autistic Presence”). In this representation, the hospital gown covers the external surface of the body but fails to protect the interior psyche from the violation of the visiting “trespassers” (HP19 4). According to Ihab Hassan, the disappearing sense of self is in response to the “ontological rejection of the traditional full subject” (37). Hassan’s deconstruction of the “self-sufficient, intact and centred subject” is represented in the lines: “The one you thought you knew is not here – / he doesn’t exist. Never did” (19). Campbell argues that it is the understanding of prevailing conditions within environments that make experiences of disabled embodiment more intelligible: “The disabled body is a site of struggle over its “signification and corresponding social meaning” (Contours of Ableism 167). For Jack Halberstam, space represents both the “sign of their exclusion and the mode by which they survive” (153). The metaphors of hospital spaces are therefore indicative of conditions which limit and disenfranchise but can also, through their representation, allow for a form of resistance.
Section Two of this chapter, “Liminal Spatiality: Traversing Institutional Spaces,” the poems “Patience,” and “Continental Margin,” represent a shift in focus: they cross the boundary between the hospital institution and the local community. These poems are particularly concerned with how the speaker finds his own sense of self in the gaps and in-between spaces. The earlier focus on enclosed spaces shifts to concentrate more on the representation of spaces of transition such as the outpatient waiting room, which denote the fluctuating movement between the community of the hospital and the domestic space of home. The speaker stands literally and metaphorically on uneven feet contemplating socio-spatial thresholds. The stance is precarious; the imagery reminds us that for the disabled citizen, placing oneself in a fixed position is often not physically tenable. Metaphorically, these poems suggest that these points of contact within space are dynamic and unpredictable, highlighting a fluid conception of embodiment. Jeffrey Willett and Mary Deegan comment that disabled people are “suspended between the sick role and normality, between wrong bodies and right bodies” (“Liminality and Disability”). Ferris’s imagery represents bodies in liminal spaces in order to emphasise the sense of being out of place and otherness.

Writing about oppression in institutional and societal spaces, Goffman argues that:

> Our sense of being a person can come from being drawn into a wide social unit; our sense of selfhood can arise through the little ways in which we resist the pull. Our status is backed by the solid buildings of the world, while our sense of personal identity often resides in the cracks (Asylums: Essays on the Social Situation 320).

Ferris represents these interstitial spaces, the “cracks” that Goffman describes, in very literal terms: bodies situated at the edges of landforms, dangling over cliffs and promontories, and hollowed out as spatial voids (320). The poems are expressions of Ferris’s preoccupation with the boundary between real and imaginary spaces of embodiment. He represents the dissolving divides of relational practices within society through the erosion of natural landscape formations, island promontories and ocean cliffs.
In the poem “Outpatient” for example, Ferris explores the fluid nature of identity through representation of the ability to cross the boundaries between the hospital space and the home (HP22). The speaker returns to the hospital as an outpatient; his status is made ambiguous as he is not wholly of the hospital as an in-patient nor excluded from it. He situates himself at the threshold between the private domestic space of the home and the familiar interior spaces of the hospital:

right up to the edge of the vortex, dangling
myself squarely in God’s line of sight.

I am not fearless – I am in the building but
still an outpatient. (HP22 3-7)

The opening figure is positioned on the edge of these spaces, initially striding towards their fate from the outside, then suspended in the internal space of the hospital room. The fluidity of their oscillating condition is signalled by the alliterative “striding” and “squarely” portraying pride in their sense of defiance (HP22 3 5). They hang limply supposedly without agency whilst waiting under the scrutiny of the doctor’s gaze but this is offset by the addition of “squarely” (HP22 5). The word choice “dangling” is placed at the end of the line (HP22 4). This has the effect of making them seem isolated and vulnerable, the word hovering in space to suggest his position is precarious. However, the enjambed “myself” grants the speaker some agency; he is poised at the “edge of the vortex” but he does not look away (HP22 4). Instead, he chooses to stare back, positioning himself in direct line of sight. As he finds himself perched precariously, as if suspended in space, the perspective shifts. The line “I am in the building” emphasises that occupying space does not confer belonging (HP22 6). This serves as an example of the way in which Ferris’s poems more broadly seek to represent the dynamic simultaneity of dwelling in space but not being of that space. These ambiguous spaces are represented figuratively as hollows, spatial voids and cliffs.
In Section Three, “Life Outside: Reimagining a New Nation,” the poems “Slouching Towards Guantanamo” and “Manifest Destiny” appropriate the language of nationhood. These poems explore the intersection between notions of disability justice and disability rights, questioning assumptions about who should possess the power to hold judgement and determine actions of governance over others. They challenge institutional structures, societal attitudes and language that dehumanises and distances by mocking the hypocrisy of policies that promise freedom and yet control autonomy. Ferris argues that “disabled people around the world continue to be subjected to oppression, ranging from violence and abuse to the ‘softer’ oppression of low expectations and limited opportunities” (Appendix 1 267). Thematically, “Slouching Towards Guantanamo” and “Manifest Destiny” disrupt, contest and reshape our thinking about embodiment and the invisible forms of social oppression.

Like other disability poets, Ferris’s poems are grounded in “politics recognising the worth of all persons” and, in resisting ableist language; they are “working to create liberation from there” (Mia Mingus “Building Back Belonging”). For example, in the poem, “Medical Imaging,” the narrator urges readers to participate in conceptualising a new world of possibilities, a space where individuals do not die from “cancer” and chronic diseases. The reader is given a list of instructions as part of the making process:

- Paint a picture of a world in which you are not dying of cancer. In which we are not all dying. In which you use only light colors, a pastel world in which there is no darkness, no shadow, no caves, no smutty dirt. (STG35 1-6)

The imperative to “Paint” tasks readers with creating an artwork in their imagination (STG35 1). The next stage is to place themselves at the centre of the newly created space, imagining how the
world might appear from this new perspective. The “pastel world” is a haven, a place of rest and harmony where the harsh opposites of light and dark are muted (STG35 4). The allusion to “caves” links to Kuusisto’s representation of perception as a type of “glacial seeing, like lying on your back in an ice cave,” an inverted, blurred perception where reality is ambiguous and illusory (P 7). In “Medical Imaging,” the “cryptic light” paradoxically reveals truth by speaking in new ways (STG35 6). Unlike Kuusisto’s poetry where the narrator envisions a private Arcadian-like retreat in the mind, Ferris’s narrator invites others from the outside to participate in building an imagined community in public space. From this collaboration, a new space is envisaged where all individuals are accepted; spatial boundaries that presently marginalise are eroded; and original language defining the values of the space is reclaimed.

Section One: Institutional Space and Structures of Containment

“Coliseum,” “Child of No One” and “Exercise of Power” are autobiographical re-imaginings of childhood experiences in hospital through which Ferris explores the gaps between past and present selves and represents this gulf in spatial terms. This line of thought disrupts the homogeneous fabric of childhood memory and overlays reality with the surreal space of the adult poet’s imagined unconscious thought. In considering the exterior and interior spaces of occupation, Ferris articulates the merging of remembered experiences reconfigured by the reflective distance and perspective of adulthood. The selected poems all explore the relationship between space, otherness, language, power, and embodiment. They re-imagine lived experience through the perspective of narrators who are visibly present yet simultaneously invisible within the societal and institutional organisations they inhabit. They crip expectations that hospitals are spaces which cure rather than deplete. Representations of hospitals as sanctuaries for the unwell
are inverted as Ferris compares them to other institutional spaces that oppress and contain: prisons, military organisations, and orphanages. The various speakers are physically located within the spaces of the hospital but are excluded from the social order that governs that space. Admittance into clinical spaces equates to giving oneself over to the rules of the institution, a transition exemplified by the crossing of boundaries: exiting waiting areas and entering reception rooms, opening doors and windows, moving through entrances and wards to specialist rooms.

In “Coliseum,” marginalisation and loss of agency is conveyed through metaphors of architectural spaces which control and oppress the body and the mind. The oppressive power of hospital hierarchies that functions within set rules and regulatory practices of the organisation is suggested by the subjection of the body to public medical examination and the handing over of personal possessions. In the opening lines, the hospital spaces are the impersonal spaces of multiple occupancy on public wards. The poem’s title “Coliseum,” denotes the sense of powerlessness of the patient: they are represented as slave-like objects acquired for sport and entertainment, like captives displayed in a public amphitheatre at the mercy of the doctors’ whims. The narrator observes “no one looks at you straight on” as if glances come from the “periphery” and the doctors as supervisors hold patients captive (HP42 4). The speaker capitulates the “I” of the first person viewpoint typically associated with accounts of personal experience, substituting it with second person “you” (HP42 2). This direct form of address is repeated sixteen times, firmly placing the reader as the active subject of the poem: the gaze is turned on them. In this way, Ferris condenses the spatial distance between speaker and reader:

On your first Monday inside you get the treatment.
They skip you on rounds, then when everyone else
relaxes and gets on with the day, you are led
through the halls —no one looks at you straight on —

(HP42 1-4)
The notion of compliance is captured in the opening line that ends with the emphatic “you get the treatment” (HP42 1). The single end stopped line contrasts with the enjambment of subsequent lines that expand on the nature of the “treatment” (HP42 1). The pun on “treatment” emphasises social practices and interactions rather than medical care. The sense of detachment within the space inhabited is suggested by the ritualised routines conducted by the anonymous “They” (HP42 2). On the daily rounds the patients are ignored until being “led” away, chaperoned through the maze of similar-looking “halls” (HP42 3-4).

Affective feelings of being spatially isolated and exposed are further suggested in the images of clothing and identity being literally and metaphorically removed upon entry to the hospital reception rooms. The metaphor of clothing is used to suggest the oppressive power of authority figures and the defencelessness of the patient. On this occasion, clothing is stripped from the body to signify the narrator’s vulnerability and exposure to the gaze of others:

to the small room

behind the coliseum. There you doff your clothes – all

of them – for the bareback gown and G-string. No cheating,

no underwear, no, nothing that the masters wear –

the keepers enforce. You sit in the cold and listen

for a clue about what lies (HP42 5-10)

The matter of fact tone is emphasized by the short lines and listing of procedural actions in the “small room” when the patient is undressed (HP 42 5). The process of undressing is presented in matter of fact imagery; each layer of personal effects is removed from outer garments to intimate “G-string” underwear (HP42 7). The removal of individual items suggests the peeling away of connections to the outside world. The poem documents a process of handing over clothing to officials that slowly erases the sense of self; individual rights are eroded and the vulnerability of the interior psyche exposed.
Each new admitant is required to submit to a physical examination in front of a large group of doctors. In “Coliseum” the body is put on display and this emphasises the inflexible unidirectionality of the doctor-patient relationship. Ferris juxtaposes the individual’s physical immobility with the bustling activity in the hospital spaces where nameless individuals move with quick, purposeful intention and “poke and prod” his exposed flesh (HP42 13). The image of the “cold-eyed” nurses indicates an intensity focussed on finding “flaws” rather than establishing a humane connection with the patient (HP42 17). The process of being medically examined emphasises the imbalance of agency between the compliant patient and the dominant doctor in this context. (HP42 16-17). Foucault’s notion of continuous supervision is applicable here as the poem denotes how the shape of internal spaces not only determines the methods of controlling the internal population but also transforms and alters perceptions of identity within it:

In that experience, medical space can coincide with social space, or, rather, transverse it and wholly penetrates it. One began to conceive of a generalized presence of doctors whose intersecting gazes form a network and exercise every point in space, and at every moment in time, constant, mobile, differentiated supervision. (Birth of the Clinic 31)

The scrutinised speaker in “Coliseum” is shaped by the space and exposes the patient’s lack of agency when linked to the idea of surveillance within hospital spaces. Surveillance in institutions can be traced back to the theory of the panopticon, a prison design by Jeremy Bentham that allows inmates to be viewed at all times from a centralised, easily managed point. Order was maintained by the central fact that the “warder’s gaze can be neither detected nor deflected by the prisoner” (Rethinking Normalcy 187). Claudia Malacrida explains how this sense of constant surveillance becomes internalised: prisoners believe they are constantly observed and thus do not deviate from expected behaviour proving the “effectiveness of the gaze” (529). Ferris’s poems are deeply concerned with the question of what it means to be subjected to a gaze, in this case a medicalised one, and to internalise these structures of self-surveillance in the context of a
modern day hospital. The confluence of invisible forces that subject individuals to the regulations and routines of conduct are represented through the motif of clothing that cover and yet paradoxically expose the body.

The viewing platform is an architectural feature of power incorporated within the building design itself. The medical staff are a seated audience of observers:

of professionals, lords of the hospital, cold-eyed
white coats trained to find your flaws, focus on failings,
who measure your meat minutely. You are a specimen
for study, a toy, a puzzle —they speak to each other as if you are unconscious (HP42 16-20)

The sovereignty of the aloof doctors is signified by their elevated positioning as “lords” within the poem (HP42 16). The patient’s status is reduced to a “specimen,” an object of curiosity (HP42 18). The external surfaces of their body are exposed for investigation by the anonymous “white coats” identifiable only by their uniform code (HP42 17). The gathering of information as an intrusive process is emphasised through the alliterative “find your flaws, focus on failings, / who measure your meat minutely” (HP42 17-18). The image of the body perched on display recalls Foucault’s observation of how power controls everyone functioning from within the societal panopticon machine: “We are neither in the amphitheatre, nor on the stage, but in the panoptic machine, invested by its effects of power, which we bring to ourselves since we are part of its mechanism” (Foucault *Discipline and Punish* 217). For Ferris, the staging denotes the asymmetry of relationships: being on the outside rather than “part of” and repressed rather than “invested” (*Discipline and Punish* 217).

In the concluding lines of “Coliseum,” the speaker is left alone, waiting in the specialist medical examination area:

already, but for commands: stand, bend, walk this way,
on this leg, on that. They forget about you for long
stretches, a kind of mercy, while you stand bare naked,
while they rehearse and renew your shame. When you are numb
through, they tire
of you, they turn you loose. You are so happy to be out
from scrutiny, so happy even for ugly clothes, for underwear,
so happy to get back to your pen, back to the ward where you are
one among many, just another kid,
almost a person again. *(HP42 21-29)*

The narrator is represented as a passive recipient of external orders and “commands” *(HP42 21).* He is commanded to standardise his body and movements according to normalised standards:

“walk this way” *(HP42 21).* As Foucault argues, these uneven power dynamics become incorporated into the narrator’s sense of self and agency; they are a product of a deeply embedded set of power relations:

> It’s my hypothesis that the individual is not a pre-given entity which is seized on by the exercise of power. The individual, with his identity and characteristics, is the product of a relation of power exercised over bodies, multiplicities, movements, desires, forces. *(Power 73-4)*

As a result of this dichotomy of spatial inclusion and exclusion, hospital institutions are invoked metaphorically by Ferris as a physically separated space, a closed off world, inhabited by a select few seeking to maintain a carefully conceived order. In emphasising spatially determined relationships of power, Ferris illustrates how space can also be made to hide consequences from scrutiny.

Ferris’s allusion to the claustrophobic, impersonal, restrictive prison-like nature of the space recalls Foucault’s analysis of Jeremy Bentham’s theoretical panopticon where institutional
power systems are described as located in observable architectural spaces designed as social control mechanisms:

All that is needed, then, is to place a supervisor in a central tower and to shut up in each cell a madman, a patient, a condemned man, a worker or a schoolboy. By the effect of backlighting, one can observe from the tower, standing out precisely against the light, the small captive shadows in the cells of the periphery. *(Discipline and Punish 200)*

Occupying institutional space in Ferris’s hospital poems is frequently represented as an inactive and passive experience - simply waiting for time to pass. In this context, space rather than history or time contextualises the nature of being. In this sense, Ferris’s representation of space as the primary means of understanding experience connects to a broader view that Rob Kitchin summarises as one in which: “Social theorists are increasingly coming to recognise that life and society are not solely constituted in time and history but are also situated, contextualised and reproduced in space” (344). The space in “Coliseum” however, represents the dissolution between the self and the institutional hospital space expressed through the sense of non-relational distance and detachment. Ferris crips ideas of connectivity and reciprocity to emphasise the disconnection between the individual, the hospital community and the figures in authority.

This sense of displacement of the self from other objects is also apparent in the poem “Child of No One” which situates the speaker as an “abandoned” homeless individual who lacks the support of parental figures (William Floyd “Orphans of British Fiction, 1880-1911” 8). At the age of five the patient encounters the organisational practices that are to become familiar routines:

Orphaned for the first time

at five – no one died –

Mom just left. At once I am waif

and ward of the Shrine – damp and trembling
clay to be molded under the sign
of the fez and scimitar.

They issue underpants,

Undershirt (sleeveless), white nylon socks,

Blue jeans, sport shirt an old man might wear

If he was small and unlucky. All

orphans are equal – all need fixing. (HP8 1-11)

The word “Orphaned” in the opening line encapsulates the sense of detachment and dislocation experienced when the narrator is left “for the first time” in the hospital (HP8 1). Nina Auerbach observes that orphans are used as a “metaphor for the dispossessed, detached self” (395).

Auerbach’s commentary on the literary place of the orphan suggests that the orphan figure occupies a liminal position in culture, detached from the voices of our literary heritage:

Although we are now ‘all orphans,’ alone and free and dispossessed of our past, we yearn for origins, for cultural continuity. In our continual achievement of paradox, we have made of the orphan himself our archetype and perhaps only ancestor. (395)

In Victorian texts, according to Laura Peters, the orphan “occupies the place of the colonised subject within society: dispossessed, without rights, and embodying a difference to be excluded” (65). The “Orphaned” narrator of “Child of No One” is metaphorically cut off, not through the process of death but due to the departure of a mother “who just left” (HP8 3). The disruptive event is described in a matter-of-fact tone, reinforced by monosyllabic details broken by hyphenated sentences. The alliterative “waif” and “ward” suggest his outcast status (HP8 3-4).

He is both an inmate of the hospital “ward” and a ward placed under the guardianship of the medical specialist protectors. The legal term expresses loss of independence and implies he is like a piece of transferable property. In his blog post, Kuusisto echoes this conception of childhood:
Of course we’re all property of some kind. It’s as true under capitalism as communism and there’s no end in sight. When you’re little you’re the property of your parents and if you lose them you become the property of the state. Some people are more ‘of’ property than others: the illusion that they are not is too costly to purchase. (“What’s the Use of Having a Body”)

The youthful innocence of the narrator in “Child of No One” makes him malleable, easily “molded” to fit new requirements (HP8 5). The space of the institution, with its enforced wearing of uniform, its rituals and initiations, deepens the sense of helplessness and passivity. The masonic association of Shriner Hospitals for Children is one Ferris himself attended. The speaker becomes like a charity case, signified by the clothing emblem of a “scimitar” and symbolic “fez” logo of the Shriner Hospital (HP8 6). The pun on “Shrine” suggests he is like a sacrificial lamb placed at the altar to undergo the surgeon’s knife (HP8 4). What is being sacrificed is his disabled identity, metaphorically cut away from his interior sense of self. In this process, the patient loses autonomy and is severed from the past. He is to be physically reconstructed to become part of an idealised homogenous group: the external shape of the body determined by the expectations and practices of the situated society.

The poem however, mocks this idea that disabled embodiment needs medically “fixing” (HP8 11). As Brueggemann argues:

We are all ‘TABs-temporarily able-bodied’: We are as invisible as we are visible. And it is only in often having to claim the rights that are due to us, to gain the access we are equal to, to enter the public space we are guaranteed, that we uncloak ourselves, turn ‘passing’ into ‘outing,’ turn discreditability into discredit. (369)

Brüeggemann’s image of “uncloaking” resembles Ferris’s metaphorical disrobing of the narrator (369). In “Child of No One” the hospital clothing signifies the illusory nature of imposed equality with the list of clothing handed out to patients “They issue underpants, undershirt
(sleeveless), white nylon socks, /blue jeans, sport shirt” (*HP* 7-9). Carrie Hertz comments:

Like all clothing, uniforms operate at a symbolic level; most importantly, this genre of clothing raises interesting questions about individuality and conformity, self-control, and the visual representation of identity. These codes dictate an “official” symbolic reading for individual elements of dress (and often appearance) and are made available to all members of a recognized and self-proclaimed group. Ideally, successful membership within the group (whether or not membership is willingly sought) is contingent on at least the superficial acceptance and adoption of the code. (43)

The replacement hospital clothing fails to instil camaraderie in a group that resists being homogenised; instead, it is juxtaposed against the “white cap” and “lab-coat” uniforms of medical staff to emphasise difference in status (*HP*). For Kuppers, stark details such as the vests being sleeveless communicates “the greatest shame: the ordinariness of it all” (“Visiting the Hospital”). The replacements are mismatched garments an “old man might wear” emphasising the sense of dislocation (*HP* 9). Ferris’s clothing metaphor is representative here of inequality and imbalance. As Claudia Theune notes, “clothing has an important function in expressing one’s social position . . . Clothing is a relevant and crucial category to express social procedures and social positioning in a multi-layered society” (493). In “Child of No One,” clothing the surface of the body connotes the enforced shedding of individual identity and superficial ideas of embodiment.

In the second stanza, the interjected colloquial aside tells us that the speaker is now on the “inside” of the hospital, and that all previous life is now on the outside (*HP* 15). This is represented as a loss of self and past: “*And our lives are theirs*” (*HP* 15). An internal hierarchy of power persists: “Nurses rule” but “yield” to the doctor “gods” and the “Chief “of “divinity” (*HP* 19). Routines replace spontaneity under the authority of the “commandants,” suggesting that the space is run like a military organisation or prison camp:
I am allowed to keep my shoes,
one sole thick with cork to make up
for my lack. Say goodbye, kid. You’re

with us now – inside. And our lives are theirs.

Nurses rule, white-cap commandants
who yield quickly to lab-coat gods
with stethoscopes, scalpels, saws. Chief
divinity is a bald, distracted gnome
with half-glasses tipped on his nose.
Weekly worship, Monday rounds. Parents
unseen, unheard, afternoon visitors,
distant kin who evoke indistinct

images of life outside the orphanage (HP8 12-24)

The hidden threat of damage in these spaces is underlined by the alliterative description of
“stethoscopes, scalpels, saws”: a triplet in which the images become progressively more brutal.
Kuppers suggests that such motifs create tension between “the violence and violations of those
beliefs in the natural body,” in ways that “are opened up” to the reader’s scrutiny (“Visiting the
Hospital”). For Ferris, pain is, in one sense, empowering: “We love our pain if it doesn’t kill me,
it makes me stronger” (“Just Try Having None” 242). Here, the narrator’s resistance to his
passive position is suggested by the visualisation of the doctor as a “bald, distracted gnome”
(19). The cumulative listing of medical conditions is emphasised by the tri-part repetition of
“until” and the climatic couplet and alliterative triplets in the final line. As the rituals and
routines of the interior space are established, memory of the external world diminishes.

This sense of detachment from outside spaces is developed in the final stanza of “Child
of No One” which emphasises the lack of belonging in either internal or external spaces. Ferris
recounts how being secreted away in the hospital provides a protective buffer between himself, others and the prejudice of the wider community:

Distancing at the charity hospital was in part about infection control, ostensibly, but it may also have been about sheltering us or quarantining us away from a society that was afraid of us, even though it might not want to realize let alone admit it.” (Appendix 1 271)

This societal “quarantining” is suggested by reference to the absence of visitors (Appendix 1 271). The resulting sense of isolation is due to factors outside the narrator’s control: they are separated and “orphaned/ by our flaws, our families, our fate” and set on an unalterable course (HP8 30-31). Ferris situates his speaker as an orphan to signify the sense of isolation, vulnerability and psychological distancing felt in being removed from the companionship of others. As Ferris observes, the social exclusion and thinly disguised prejudicial attitudes are still commonplace for some:

I also find myself thinking about the distancing we experienced, that was a central part of that experience—especially in light of the direction for social distancing as I write this in the face of the coronavirus pandemic. And I wonder how different they are. (Appendix 1 271)

The subtlety of “Orphaned” in the opening phrase of “Child of No One” comes from its capacity in this stanza to condense the spaces between the reader, narrator and the other patients into a collective “We.” Spaces of socially and medically produced differences are compressed. Kuppers notes “We share roots, and many stories, but our different twang, our own breath animates these stories, making them sing as they are compressed against our specific bodies” (“Disability Culture Poetry”). To end the imposed orphaned otherness, the disabled patient in this poem is forced to normalise and “sacrifice” his abnormal body in order to obtain re-admittance into society (HP8 25). However, the implication is that we are all orphaned by
societal ideas and policies that limit our boundaries, our place in the world, and dictate intersections with others:

But until we make our sacrifice,
until our bodies are corrected,
until the gods deign to let us go,
we are children of no one,
wards of the Shrine, patronized
by jolly mystics in fezzes, orphaned
by our flaws, our families, our fate. (HP8 25-31)

The dominant forces of the doctor “gods” define and maintain the mechanical structures of the narrator’s daily existence, represented by the routines enacted by medical staff (HP8 27). Ferris crip
t the specialist power of “jolly mystics” to communicate the larger problems that exist within a society that views medical care as an individual rather than collective responsibility (HP8 30). Ferris represents the confluence of forces, including regulations and routines, that structure life in hospitals, according to Alice Street and Simon Coleman, control and isolate patients as if they inhabit “islands defined by biomedical regulation of space (and time)” (5).

In the poem “Exercise of Power” Ferris also represents the speaker metaphorically as an orphaned other, an individual bereft of family relations and severed from cultural norms. On this occasion, metaphors of distancing, detachment and containment crip the enforcement of abstract institutional power which strips away rather than replenishes selfhood. Ferris reveals the reductive, distorted reality of manipulated bodies which so deprive individuals of personal agency that they are “orphaned” in the process. Instead of being made whole they are left bereft and without a language that communicates the experience:

The orphanage retained an unhappy dentist who
picked at our fillings and called out to an assistant
where they were. I did not know the code then: a number, occlusal, mesial, buccal. Amalgam. Each tooth was mapped by a malcontent cartographer who wore a pale yellow nylon shirt, buttons off to the side. Sickly disinfectant was his signature mouthwash, deodorant, and cologne. (HP24 1-8)

Medical language is conveyed as a barrier to understanding the specialist procedures, a secret “code” used by a distant group of professionals. For Foucault, the control of language is a key feature of these institutional settings, a way to “discipline the body, optimize its capabilities, extort its forces, increase its usefulness and docility” (History of Sexuality 139). “Exercise of Power” highlights how language erects barriers that reinforce practices that exclude and makes bodies passive. At this meeting point of language and culture, the “interrelationship and interpenetration of power by culture and culture by power is framed,” meaning that individuals face multiple, interlocking, societal, environmental, linguistic and organisational prejudices (Turner 116). Ferris suggests that understanding cultural codes and prejudices is something only learned by experience and exposure to them: “I did not know the code then” (HP24 1-8). According to Turner, the interlocking systems of repression are layered and “embedded within the meaning system of any social group” (116). They are based on assumptions “legitimising the power of some” over others, and on the advocating of the “matrices channelling/enabling the social enactment of such power” (Turner 116). This hierarchy of interconnected linguistic and physical exclusion is conveyed in the concluding lines of the opening stanza:

Seldom did he
bother to address us. To get to his yellow room
at the end of the hall we had to pass the nurses’
lounge, the cast room, the recovery room on the right,
and on the left those double metal doors with high windows,
the large green room where no orphan was conscious for long. (*HP*24 8-13)
The prison-like interiors with high windows prevent access to outside views and control access with “double metal doors” that exclude entry and prevent exit (*HP*24 12). The speaker envisages the contained spaces as a series of closed off walls, “halls,” floors and restricted spaces (*HP*24 9). Spatial confinement within is suggested by areas designated for specific purposes: the examination room with its “yellow” interior is situated amongst an inner maze of specialist rooms (*HP*24 9). As Rosemary Gillespie indicates, a key component of architectural arrangements is that of imposing physical separation, reinforcing ideological distinctions between individuals:

. . . difference was embodied within the geography and architecture of the clinic through two quite distinct areas; an outer area, consisting of entrance hall, toilets, receptionist desk and waiting area; and an inner area, separated by double glass doors, consisting of consultation and examination rooms” (216).

Similarly in “Exercise of Power,” the blurred glass suggests the restriction of status and the difficulty of establishing a sense of self-image in the anonymous surroundings of the hospital:

Everything seemed so ordinary those quiet days.

But the green sanctum with tile walls was never open –

I could never see much through the glass, never enough
to shake the fear or let me know what really happened
in that room where everyone wore a mask. (*HP*24 14-18)

The “green sanctum” is an uncharted space that he is aware of but cannot physically access or see through the veil of “glass” (*HP*24 15 16). In Kuusisto’s poem, “Post Orphic,” the green space is also the space of the imagination, an Eden-like haven that he can retreat into: “Tonight I felt it in my ribs: / A flood of green in the marrow”(*OB* 28 1-2). For Ferris, the green room in
“Exercise of Power” is not a space of rebirth but a sterile and claustrophobic operating theatre: the space where bodies are ‘corrected’ and limiting societal stigmas are reinforced. The individual remains confined to a spatially reduced routine existence, functioning within limited areas, separated and controlled by staff who wheel him about. The image of the doctors and medical staff wearing “masks,” accentuates the anonymous uniformity of a staff who are collectively grouped as mysterious authority figures without individual identities (HP24 18). The image of the “mask” is also suggestive of linguistic barriers, linking back to the earlier sense of isolation from jargon and medical rhetoric.

The disconnect between the narrator and medical professionals is extended through the sense of specialised spaces like operating theatres and consultation rooms being restricted areas within the hospital. The closing off of levels between wards emphasises the continued exclusion of patients from specific spaces:

We were not
to loiter on our trips up to the second floor,
but I was drawn to that room, I would have explored it,
I would have hidden away to watch the exercise
of power, the defiance of what God hath wrought,
affirming then fixing divine errors, claiming
a brighter tomorrow for orphans, for cripples, for
those who must suffer for God’s mistakes, who must be wheeled
into the large green room to fix what is wrong with us. (HP24 18-26)

Ferris resists the labelling and discriminatory groupings of disabled individuals, here addressed as “cripples” and “orphans” (HP24 24). The language is indicative of the stigma associated in being viewed by the hospital establishment as undesirable beings who must be corrected and “fixed” as in “cured” (HP24 26). The authority within these enclosed spaces is located in the
anonymous medical figures who move, control and separate the compliant patients and give false hope of a “brighter tomorrow” (HP24 24). The experience is presented as a recurrent nightmare as the speaker is unable to build a picture of past events even though this experience of passing extended periods of time recuperating within the confined institutional boundaries is recounted from the perspective of the adult poet.

Ferris contrasts dynamic socially constructed sites with static, ritualised hospital routines in order to express the experience of being spatially separate, at odds and feeling “out of place” (Kitchin 345). Kitchin outlines societal modes of exclusion where cultural, institutional and organizational barriers have to be navigated:

As an active constituent of social relations, space is socially produced to exclude disabled people in two main ways: spaces are currently organised to keep disabled people ‘in their place’; spaces are social texts that convey to disabled people that they are ‘out of place.’ (344-345)

For Ferris, the interior architectural spaces of confinement represented in “Coliseum,” “Child of No One” and “Exercise of Power” are both real and metaphorical spaces of control and disenfranchisement. In this sense, Ferris locates his own experience within a much longer history in which disabled people in the United States have been pathologised, criminalised and contained within institutional spaces, socially isolated from families and communities. As Rachel Dudley observes, “By the early twentieth-century charity systems, asylums, alms houses, rehabilitation centers and various other institutions had been developed to contain people considered insane, the blind, deaf, and/or ‘multiply-handicapped’” (“Toward an Understanding of the ‘Medical Plantation’”). In his poetry and his criticism, Ferris highlights the danger of such systems which strip individuals of selfhood and autonomy through procedures that erode rather than sustain. More broadly, Foucault outlines how institutions use power to enforce control on others:

The exercise of power is not simply a relationship between partners, individual or
collective; it is a way in which certain actions modify others. . . Power exists only when it is put into action, even if, of course, it is integrated into a disparate field of possibilities brought to bear upon permanent structures. This also means that power is not a function of consent. (“Subject and Power” 788)

Stephanie Rutherford, writing on how power and space are enacted, notes that “different bodies are incorporated into governmentality differently (or not at all)” depending on social location (303). She adds, “Power is enacted somewhere – not just as a metaphor but a spatial reality. Power works through institutions, governments, corporations and bodies that are material and particularly located” (303). Ferris illustrates that the “specificity of power” governed through the space of the hospital is indicative of power, authority and rule “applied differently” to disabled individuals (Rutherford 303). This inequality is a central theme of Ferris’s poems which crip environmental factors and practices that actively disenfranchise disabled people. He explores this lack of agency as rupture and disconnection of societal and parental relationships. He troubles connections between the self and the outside world and represents them spatially. He crips the relational contour between past and present selves to establish the gulf between representations of how they are, not as how they are perceived by others. In considering the exterior and interior spaces of occupation, Ferris articulates the merging of remembered experiences reconfigured by the reflective distance and perspective of adulthood. Ferris also crips perceptions of authority within spaces by complicating the practices and ownership of public and private spaces. He highlights the ambiguity of being included and excluded by those who invisibly govern the space.
Section Two: Liminal Spaces in Ferris’s Poetry

In a marked contrast to the tightly controlled interiors of the hospitals of Ferris’s poetry about childhood experience, the poems “Patience” and “Continental Margin” describe the dramatic spaces of unexplored and untamed outdoors. They represent processes of movement and moments at which narrators are standing on, dangling over and crossing intersecting boundaries of unpredictable spaces. They explore ideas about the mutability of selfhood in spatial and temporal terms. Drawing on a myriad of recalled moments and encounters from the past, the speakers are situated on precipices and edges of re-imagined spaces, reaching out to a world that extends beyond the confines of the hospital space. They are simultaneously located in the liminal space between belonging and being other: “I live in the narrow space/ between two worlds” (“Pater Noster” 2-3). Liminality as a space of transition originates from the Latin word limen, meaning “a threshold,” signifying the passage from one status to another and defining the movement between the different states. Arnold Van Gennep first coined the term “liminal” to explain the tripartite process of separation, liminality and aggregation involved in the “rites de passage” which mark the stages of childhood and adolescence into adulthood (134). According to Roz McKechnie, the liminal space of the hospital is a site of transition:

Hospitals are ultimately liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed etc. For many people, hospitals are places in which their previous identities . . . are stripped bare. New identities . . . are forged. (73)

The speakers in “Patience” and “Continental Margin” hover over and stand at the edges of spatial voids contemplating the past and the future in the liminal space between them. In this liminal space between childhood and adulthood, they are suspended between realities, unable to
transcend fully the confines of the hospital or reach the landscapes that reside just beyond its boundaries. They stand at the border, in the interstitial space, at the meeting point between worlds, reaching forward and backwards through time and space.

The poem “Patience” presents a young adult narrator situated outside on a promontory that juts out into the ocean in a natural landscape that is expansive, wild and unpredictable. The hospital building is literally perched on a cliff top overlooking the water. The speaker by contrast is poised both literally and metaphorically at the edge, standing in a precarious position ready to “topple” into the sea of the unknown, transitioning metaphorically between one spatial reality and another. The implicit dialogue emanates from the collective “we” of the reflective adult-patient perspective:

The hospital is on a promontory jutting

Far out into the ocean. We’re on a cliff, about

To topple into the waves which smash against the rocks. (HP6 1-3)

The external, outward-looking viewpoint suggests how the patients are situated on the edges of existence, set apart, “Far out” and away from all that is familiar (HP6 2). The “we” simultaneously reminds us of our proximity - all are included in the imminent fall (HP6 2). The coastal nature of the image is particularly important for conveying the sense of isolation but also constant shifting. As Bonnie McCay argues:

But coasts are also liminal, in-between and both land and sea, bathed by both tides and “run-off,” sculpted by forces of wind and waves that intersect and play upon the consequences of plate tectonics and bulldozers. Their boundaries are often vague, shifting, and contested. (8)

The institutional space is represented as a separate community, an island of limited horizons. Street extends this metaphor, arguing in a broader context that that hospitals have been “presented either as isolated “islands” defined by biomedical regulation of space (and time) or as
continuations and reflections of everyday social space that are very much a part of the ‘mainland’” (5). In “Patience” the space between the island hospital and the mainland streets of the wider community is obscured from view: the “thin tongue” connecting them has been eroded by nature (HP6 5). The eroding force of nature dissolves the gulf between communities. In temporal terms, the speaker compresses the gap between past experiences “behind us” and his present adult self:

We can’t even see across the street - there is no street
no one can reach us, the thin tongue of land behind us
has crumbled into the sea. Hail drums windows,
thunder rattles the glass until it must break, the lights
go out. (HP6 4-8)

Common physical aspects of the outside environment appear to flicker in and out of existence. The “street” connecting to the external community is erased from the space emphasised by the caesura in “across the street - there is no street” (HP6 4). The rural and coastal landscape connections have “crumbled” in a natural process of erosion (HP6 6). Ferris’s image of the power of nature reshaping the landscape offers the possibility of reconstructing spaces that have often excluded people with disabilities.

Reclaiming the space is figured in “Patience” as a dynamic process, symbolised by breaking the glass window, fracturing the barrier between the inside and outside spaces. Ray Land et al. argue that liminal spaces represent “a state of partial understanding, or a so-called ‘stuck place,’ in which understanding approximates to a kind of ‘mimicry’ or lack of authenticity” (x). Ferris undermines Land’s notion of being “stuck” with images of nature as a force which “rattles” and makes visible when “the lights/ go out” (HP6 7-8). Land argues that the experience of crossing “thresholds can be exhilarating but might also be unsettling, requiring an uncomfortable shift in identity, or, paradoxically, a sense of loss” (x). Although confusing and
unpredictable, Ferris’s poem suggests this process of change and loss is simultaneously cathartic and hopeful:

Our island washes away beneath us, wave by wave
it gives us away until we slide down what is left
of the cliff into the alien sea and bob there,
rudderless, our casts and the ether our only friends,
and wait to see what happens next. (*HP6* 12-16)

The insulating boundary of the island that keeps interactions separate is washed away. The allusion to the erasure of presence through time which exposes and “gives us away” reminds us of John Donne’s famous lines expressing the interconnectedness of all people: “No man is an island, entire of itself; /every man is a piece of the continent” (“Meditation 17” 1-2). The assertion in Donne’s “Meditation 17” that we are stronger together as “part of the main” resonates with Ferris’s thinking that we thrive as part of a greater community (2). In “Patience” the word “alien” represents the sense of being foreign, of no particular place, cast adrift and marginalised both within and outside the hospital community. Yet there is a sense of optimism from the lightness of the word “bob” and the suggestion of future potential in the anticipatory phrase “what happens next” (*HP6* 14-16). Ferris links the dramatic landscapes with the external hospital spaces to suggest the collapsed distance between traditional thinking and new ideas of community life.

The outdoor landscape described in “Continental Margin” represents the border between spaces of the past and the future self. The speaker stands at the edge of a cliff, where one slight shift of movement has the potential to plunge them into the abyss of the unknown. It extends representation of this precarious existence by depicting mountain ranges as a means of examining society, cultural and linguistic barriers. In Ferris’s poem, however, there is a shift in stance from the sense of vulnerability of the earlier childhood poems: the speaker now stands
self-assured, confident in his sense of belonging. The opening single line sentence “I am safer here.” is an authoritative statement of self-knowledge (STG37 1). Placed strategically, it sits end-stopped, suspended metaphorically and visually above the asymmetric lines of the poem’s fragmented form:

I am safer here.
I will not slide off
the edge of the continent
into the abyss which awaits
there just on the other side
of the mountains. Those who dare
the abyss call me tame,
staid, stolid, a little lame,
flat, plodding, not very
daring, seductive or chic. Perhaps
they are right. (STG37 1-11)

The opening statement of five syllables is followed by a second of equal metre; this amplifies sibilants in “safer” (STG37 1). The word choice “Slide” is matched by the metrical placement of the sibilant “ss” of “abyss” (STG37 4). In “Continental Margin,” the action of sliding echoes the preoccupation with falling and loss of control. The spatial imagery shifts from the “edge” to encompass the vertical heights of “mountains” and the vast depths of the cavernous “abyss” where a caesura imitates the abrupt ending of space in written form (STG37 6). David Terry alludes to the transient, impermanent nature of human experience as being something more than the “empty container or static background in which time’s performances unfold, that space is not the absence of stories, but a charged encounter . . . not an empty void that must be crossed” (336). The speaker stands in a safe, creative space which allows him to have a firmer hold on his
sense of self. The regularity of the poem’s visual structure is achieved using pairs of asymmetrical feet with the trochee employed to mimic the “stolid” and “plodding” movement of feet accompanied by the sibilant “staid,” “stolid,” “seductive” and end stopped “chic” (STG37 8-10). The monosyllabic statements reinforce the simple sentence structures and create the sense of a childlike language which belies the abstract adult nature of the concepts expressed.

The title of the poem “Continental Margin” suggests a spatial positioning between different physical states. In geographical terms, the “continent” is a continuous expanse of land stretching out across the known world (STG37 3). These land masses are not divided into countries with mapped geo-political borders but are areas surrounded by oceans. Larry Doyle explains that in geology, the continental margin marks the “transition to the deep ocean basin” and is the divide between the “continental and oceanic crust” and the site of “geological activity” (“Continental Margin”). In addition, the continental margin is the term for the hidden “submarine edge of the continental crust” and the collective name for the underwater levels that fluctuate and encompass the “continental shelf, continental slope, and continental rise” (Doyle “Continental Margin”). The margin, therefore, demarcates the edges of land at the shoreline. Ferris appropriates this geographical mapping terminology and combines them with metaphors of separation and otherness. The abyss “awaits” as we metaphorically sit on the cusp of decisions which lie ahead. With an apparent detachment, the narrator lists monosyllabic examples of name calling labels, cataloguing his apparent failings until the poem’s argument pivots on a “But” and the spatial momentum juxtaposes “they,” the unidentified fickle “others” who “flirt” and tempt “fate,” with the collective “we” of the marginalised and excluded (STG37 11-15). The repetitive use of “we” and “they” amplifies the contrast of different techniques of crossing the continental margin at the end of the poem:

    But while they fly
    over to the other coast,
flirt with the other abyss,
and congratulate themselves
for again tempting a fate
which ignores them for now, (STG37 11-16)

This idea and the notion of delicately balanced and shifting liminal thresholds is also found in Ferris’s representation of crossing over the mountain ranges to join the coast below. In a play of parallelism, Ferris’s narrator compares his controlled movement to the reckless journey of those who seek more quickly to cross the spatial divide. His neighbours “fly” and “congratulate themselves” for mastering their environment (STG37 11). In a seer-like prophecy, the narrator highlights the unseen dangers in “tempting a fate” that “ignores them for now” (STG37 16). It is an example of Ferris’s poems which probe at the boundaries of definition, marginalisation and representation, challenging conceptions not simply of what it means to be disabled but expanding thinking about what it means to be human. Ferris argues that:

Disability is dangerous. We represent danger to the normate world, and rightly so.

Disabled people live closer to the edge. We are more vulnerable or perhaps it is that we show our human vulnerability without being able to hide it in the ways that nondisabled people can hide and deny the vulnerability that is an essential part of being human. But there is something glorious in being considered so odd, so marginal to society. Disability brings with it a wonderful range of remarkable and powerful vantage points. (“Disability and Poetry” 272-273)

Ferris describes disabled embodiment as being “closer to the edge” and these metaphors of being at border crossings, margins, tottering at the cusp or stuck between boundaries are motifs that conversely emphasise the “vantage points” of resistance and disrupting control (“Disability and Poetry” 273). Casey’s comments on human existence capture the unpredictable nature of life that we all face: “We live in an uneasy world in which humans teeter on the brink, not knowing what
to expect the very next moment. This is a world of very high risk . . . ” (xvi). In “Continental Margin” the flighty “they” is contrasted with the deeply rooted, grounded “us” of a disabled community that is succeeding in planting firm roots:

my people plant their feet deep,

we drink from deep waters,

we sow and reap in the sun,

we sing into the wind

which rushes from one abyss
to the next. (STG37 17-22)

The use of verbs “plant,” “drink,” and “sing” conveys an active, collective force in harmony with nature. The internal architectural structures of the hospital space shift to the fertile, rural landscapes of the outside. The adult-patient perspective creates an idyllic setting through his imagination, employing biblical language to invoke celebratory refrains and psalms of praise. This connection between people, nature and the spiritual world offers a complex, celebratory vision of a disabled country with a song that sings as a united voice. Its vision recalls the sentiment expressed in Neil Marcus’s poem “Disabled Country”: “If there were a country called disabled, I would be from there” (“About”). For Ferris, the imagined space is not separate and somewhere “there,” as it is for Marcus, it is situated here, in the “narrow space” liminal spaces of existing structures (“Pater Noster” 2). According to Keating, these borderland voices give insight as they offer a “perspective from the cracks”; namely, a different perspective on borders between identities and “systems of difference” (9). Gloria Anzaldúa suggests these types of spatial “borderlands are physically present, wherever two or more cultures edge each other, where people of different races occupy the same territory, where under, lower, middle and upper classes touch, where the space between two individuals shrinks with intimacy” (19).
Imagining a collective space, shrinking the void between contours, Ferris collapses the space between past and present and outlines how standing at thresholds can allow us to look back across spaces travelled to reflect on progress:

It is so much easier to see when you can gain a little distance, a little perspective. Some of what we see is peculiar to disability as suggested in Stephen Kuusisto’s “Harvest,” in which the speaker admires ‘the white moon of the morning, / even if my eyes tell me there are two moons.’ But most of what we perceive isn’t peculiar to disability — it’s peculiar to human life. And that’s what we need to be writing. (“Disability and Poetry” 273).

For Ferris, disability poetry offers a vehicle for examining the “peculiarities” and idiosyncrasies of embodiment and the borders and boundaries that affect experience (“Disability and Poetry” 273). By looking from the vantage point of the atypical, the perspective shifts to a comprehension of the whole. Willett and Deegan have recently sought to link disability to the concept of liminality as an ambiguous state of suspension between rejection and acceptance in a society focussed on body difference. They argue that “certainly, those with disabilities seem to occupy an ambiguous state; they are neither sick nor well” (“Liminality and Disability”). Ferris crip[s] such misconceptions of disability as a suspended, precarious state by representing community consolidation through the dissolving of edges, voids, borderlands and gaps between relational contours. The reductive process compresses perspectives of difference and opens the space for envisioning new collectives.

Section Three: Life Outside: Reimagining a New Nation

Ferris ascribes crip poetry with a metamorphic agency, one with the potential to “transform the world” (“Crip Poetry”). It is this focus on the global scale of his ideology that propels his poetry from reflective preoccupations of the disabled self in *The Hospital Poems* and shifts to an
outward-looking engagement with the complexities of narrative, nationhood and humankind in the later collection, *Slouching Towards Guantanamo*. Whilst Ferris never loses sight of the individual and the particular, he expands his spatial lens. In Ferris’s critical interview, “Disability and Poetry,” the subjective “I” viewpoint transforms into the collective “we”: “We. I presume, I claim an ‘us,’ even though there are myriad ways of embodying (and denying) disability, and no two disabled people’s experiences are the same” (“Disability and Poetry” 273).

The poems “Slouching Towards Guantanamo” and “Manifest Destiny” reclaim the language of nationhood as a central component in reframing society from a disability perspective. They satirise the tales of American progress by representing the lived reality of those whose narrative is excluded. The speakers “sing” different versions, juxtaposing the language of American forefathers with the figurative voices of the ignored and censored (“Poet of Cripples” *HP*ix 14). They appropriate linguistic patterns of language from political speeches and manifestos and reconfigure embodiment in new cultural imaginings of ways of being in the world. As Ferris argues:

Each poem, as well as each other form of art, has the potential to contribute to that great cultural storehouse of possible images - which includes possible ways of being in the world. Each time we contribute to that great storehouse, we have the potential to enlarge the range of what is possible to imagine in that culture. Poems can help make the world more possible. What could be a greater gift than that? (Appendix 1 271)

For Ferris, the poetic process of engagement with this “storehouse of cultural images” and raw materials, invites readers to reconsider ideals that reinforce notions of difference (Appendix 1 271). These ideals are formulated from iconic words, images and colonial tales of expansion from the white, Western viewpoint that are understood in distinctly spatial terms: as a series of layers. In “Slouching Towards Guantanamo,” a series of citations place his poem within a widening literary context. For example, Ferris engages in a dialogue with William Butler Yeats’s
poem “The Lake Isle of Innisfree” through the image of building new spaces: “Let us arise and
go now, and go/ to Guantanamo” (STG33 1-2). There is a “slippage between past, present, and
future” in Ferris’s poetry and this effect is created through the way that he revisits written and
spoken texts, memories, and appropriated language from literary sources and legal charters on
rights of citizenship and the American constitution (Simchi Cohen 254). In this way, his poetry
articulates the overlapping voices of the marginalised through time and space to achieve a
perspective on both the present and the past. From this synthesis, a vision of a future space
emerges.

“Slouching Towards Guantanamo” and “Manifest Destiny” envision potentialities of a
disabled country evolving from political discourse, literary allusions and linguistic cultural
antecedents. As creative poetic manifestos, they call for change in our thinking about societal
organisation and embodiment, creating new countries from past ideals. The concept of imagining
new territories is similar to Kuusisto’s imagined planet as a constructed abstract space: “On the
planet of the blind, the citizens live in the sirus of cricket wings twinkling in inner space . . .
unvexed, the mistaken discover new and friendly adjacent arms to touch” (P 148). Kuusisto’s
imaginary “citizens” dwell in an “inner space” within the natural world whereas Ferris’s citizens
are involved in the joint process of making an imagined future space.

The collective enterprise is represented in “Slouching Towards Guantanamo” through the
layers of different ideals, dreams and imagined spaces of future hope from a variety of biblical,
literary and political discourses. For example, the opening lines “Let us arise and go now, and go/
to Guantanamo” is an allusion to the New Testament passage from St. Luke: “Let us now go even
unto Bethlehem, and see this thing which is come to pass” which symbolises the Christian hope
for the future in the birth of Christ (Ch2 15). In addition, the line is also a reference to T. S. Eliot’s
“The Love Song of J. Alfred Prufrock”: “Let us go then, you and I” (Prufrock and Other
Observations 6 1). The poem’s eclectic phrasing and cadence shifts between sources from various
voices and periods. It documents movement through time and space by representing the imagined journey of immigrants crossing from the known territories into the unknown new world, like the first travellers exploring America. The opening lines reshape a new site of residence in the promised land of Guantanamo:

Let us arise and go now, and go
to Guantanamo, let us dream of snow,
and build a nation there, once upon a time
when we could freely breathe the air, we’d no
need to make up plights to scare us so,
adventurers would always go abroad to find
what’s there – and bring back booty and new frights.\textit{(STG33 1-7)}

The idyllic notion of the American frontier as a period without fear is suggested by “when we could freely breathe the air” (\textit{STG33 4}). However, Ferris crip[s the idea that fear is only found outside the borders of America by using the archaic word “booty” reminding us that this is an idealised story of freedom and that these “adventurers” are more likely to be slave traders (\textit{STG33 6}). Arpita Sawhney’s articulation of the disconnection between dream and reality of how black Americans “enthralled by the utopia of the American Dream and, on the other, they were pained by the bitter reality of racial discrimination, poverty and social injustice faced by the blacks in America” is also signalled by the poem’s reference to “frights” (\textit{STG33 1-7}) (619). From this satirical perspective, past glories are less certain and their celebration becomes more ambiguous. For example, the poem’s title “Slouching Towards Guantanamo” and the poem’s ending refrain both evoke Yeats’s line “slouching towards Bethlehem to be reborn” (\textit{Michael Robartes and the Dancer} 19 22). The apocalyptic epic, “The Second Coming” expresses Yeats’s sense of horror at what might happen to civilisation as World War One devastates Europe. Ferris’s allusion makes us consider the connections between Yeats’s vision and Ferris’s
representation of the nightmare of present and future policies enacted against minorities. The juxtaposition of ideas distils the gap in time and space to suggest an impending urgency.

Indeed, “Slouching Towards Guantanamo” expresses a similarly shocking prediction for mankind’s future represented by the image of the devouring self: “our own bodies /turn on us” (STG33 9-10). The narrator’s demand for individuals to rise anew recognises the need to redress the harm we are doing to ourselves. Ferris remarks that this is what poetry has the power to achieve:

Who “we” are is always shifting. Is disability, or whiteness, or maleness most salient in this moment? Or poetness, vegetarian-ness, musician-ness, or on and on? I don’t demand that poetry or any other art form serve utilitarian goals, however laudable they might be. But I do want poetry, including my own, to open the world, to pay attention to what is, without getting stuck there. (“Disability and Poetry” 273)

Even as it imagines other countries and future worlds, Ferris’s poetry insists “we must pay attention to what is” and distinguish everyday reality from the ideals encapsulated by the American Dream. The poem’s title “Slouching Towards Guantanamo” and its themes invert the American Dream of liberty by presenting an alternative reality of internment camps erected in opposition to intellectual freedom. The analogy of a people with disabilities to prisoners in Guantanamo extends Foucault’s image of the prison as a site of institutional power. The Guantanamo Bay detention camp was established by President Bush’s administration in 2002 during the so-called “War on Terror.” The association of disabled people with persons detained without trial is a shocking representation of societal oppression and connects back to the stultifying institutional interiors of Ferris’s Hospital Poems. Garland-Thomson outlines the extreme form these attitudes can take, when governments tell “us that our world would be a better place if disability could be eliminated. Enacted worldwide in policies and practices that range from segregation to extermination, the aim of eugenics is to eliminate disability and, by
extension, disabled people from the world” (“The Case for Conserving Disability” 339).

“Slouching Towards Guantanamo” highlights that disabled individuals do not automatically
thrive in society. It reminds us of the battle against prejudice, known and unknown threats and
challenges of society’s own making:

No mind,
the prophecy is clear – it’s a jungle out there,
our only choice is fear – if nothing can be sole
or whole that has not first been rent, do they
who threaten favour us, or do they simply lead
to government? (STG33 24-29)

The representation of the speaker as a prophetic seer in this poem reminds us how information
can become a source of power especially when society fears threat from unknown sources. The
enjambment connects disjointed thoughts so that these unseen forces are threaded together with
the repetition of “do they” until the “they” becomes linked to the “government” (STG33 29). The
combination of caesura and fragmenting hyphens convey an edginess and anxiety characteristic
of language patterns that convey mental confusion. The line “it’s a jungle out there, our only
choice is fear” is a parody of Willy Loman’s iconic lines from Arthur Miller’s Death of a
Salesman (STG33 25). Ferris’s citation in “Slouching Towards Guantanamo” references
Loman’s optimistic utterance “the jungle is dark, but full of diamonds” which is then countered
by the revelation “the woods are burning” (115 and 31). The image reminds us that vision can
distort, promising riches when reality proves harsher.

The speaker in “Slouching Towards Guantanamo” calls for the dream to be redefined, in
part, by those who are excluded from it. The verse begins and ends with a cry to rise up and go to
Guantanamo in a refrain that echoes a biblical return to the Promised Land. The reference to
“sin” is optimistic in its redemptive power. If individuals collectively have the capacity to face
the “past” the process promises to be cathartic (STG34 37). The message of regeneration leads to the re-imagining of a land of potentiality, rich in ideas and “golden in /this capillary light” (STG33 29-30). The return to an imagined alternative world connects to a distinction that Melanie Lörke makes between “knowledge worlds” and “wish worlds” (178). In the knowledge worlds, “the operators are knowledge, belief and ignorance” and in this context, the speaker-as-operator has knowledge of the parameters of his existence and the rules and regulation he is expected to follow. Wish worlds, however, involve “dream fantasies and fictional stories” in a realm that is “only entered through reentering” (Lörke 178). Ferris’s speaker aspires to re-enter the wish world of Guantanamo and reject the knowledge world which manipulates and marginalises through propaganda and stigma. In its associations with dispossessed peoples, the imagery used recalls the diasporic plight of the Israelites who wandered homeless, suffering displacement and false imprisonment:

enough – so let it snow, and let us go, and go fast

to our Guantanamo, and there begin

redeeming sin, and there at last to face our past. (STG34 35-37)

The “us” travellers are journeying to a place that simultaneously exists as a homeland but also, paradoxically, denies the existence of its own citizens (STG34 35). The narrator indicates that we are bound to the past but not chained by it; recognising that the malleable nature of ideas is central to progress. The internal rhyming assonance of “o” in “so,” “snow,” “go” and “Guantanamo” creates a nebulous, overlapping aggregation of citations, associations and memory traces that reshape the original meanings (STG34 35-36). The rhyming of “fast,” “last,” “past,” “begin” and “sin” interconnect ideas forming a constellation of images (STG34 35-37). The generative process comprises an imaginary capable of acknowledging and confronting the past. According to Kathleen Kirby, it is important to acknowledge “distinctions between all of the forms of space that shape our being” (189). By documenting the movement across
boundaries, both geographical and temporal, between old and new, the narrator transforms what Kirby terms a “responsive and responsible model of the subject: one that abandons neither political realities nor personal histories, nor arrests possibilities for change” (189). The narrator in “Slouching Towards Guantanamo” confronts truths and challenges the regulatory powers that bind and exclude. Part of the poem’s power and resonance arises from the central conceit: the playful dreaming of a new, fantastical and better world as a “form of escape” from the confines of the past (Frederic Shepler 20).

By contrast, the poem “Manifest Destiny” is inspired by past ideals which are cripped to undermine present fears of otherness represented through America’s war on terror. It explores the notion that some disabled people are more threatened by the enemy dwelling within society than the perceived external threats of unknown outside forces. It addresses the poetics of belonging and nationhood in the aftermath of colonialism, 9/11, and in the context of transnational migrations. Ferris formulates a compelling argument for rethinking contemporary politico-sociological ideology of nationhood and posits a reconfigured one that is an inclusive spectrum of disabled communities. The repetitious “I” first person viewpoint establishes a structural patterning of expectation which can then unexpectedly shift to directly address readers. This disrupts anticipated phrasing and fragments the configuration of pivotal speeches to intersect literary and political idioms, puns, allusions and cultural references in a continuous dialogic. The 128 lines of verse form an underlying structural framework allowing the narrator to voice a plethora of concerns regarding the treatment of the disabled communities in American society. It positions contested modernities and contemporary culture alongside political discourses and myth-making “stories” from the past to refresh and renew the context (STG26 3):

I see you, America.

I am your dying son.

I recall your stories
of hope and of glorious
trails to true freedom.

Give me liberty, go west, go deep.

One small step one giant (STG26 1-7)

In the opening couplet, the narrator claims heritage both as a “dying son” and as part of the collective recalling the “stories” of past frontier “trails” as wagon trail travellers head West “to true freedom” (STG26 5). Ferris parodies the notion of freedom, adopting a patriotic tone through triplets which salute America’s socioeconomic opportunities in commerce, migration and individualism. The appropriation of quotations from other works produces an interplay between the original voices and the voice of the narrator. The quotes “Give me liberty” and “go west” actuate an emotional response which merges with the new phrasing, condensing the relational distance. The integration of laconic statements creates a montage of connections which fuse together in a collage of images and ideas.

In “Manifest Destiny,” Ferris layers ideas and allusions, appropriating the language and styles of oration and declamation from the impassioned voices of American dreamers, including a direct citation of Thomas Jefferson’s famous lines “We hold these truths/ to be self-evident” from the Declaration of Independence (STG26 13-14). Similarly, Martin Luther King Jr. set out his manifesto for racial equality in his seminal speech at the Lincoln Memorial in Washington. Ferris overlays present concerns with the historic argument that the “unalienable rights outlined in the Declaration of Independence should be extended to all people in that country regardless of their race” (Mike Kent et al. “Introduction: why manifestos, why now?”). He emphasises the liminal gap between aspiration and achievement as a continuous presence through the caveat of “but” and “right here”:

I have a dream, America. Ask not.

I have lost my way, America,
but I’m right here with you. (STG30 111-113)

The famous phrasing of “Ask not.” is abruptly curtailed, inverting the directive (STG30 111). The admission that the way is “lost” suggests an unravelling of intention, crippling the notion of a predetermined path and juxtaposing it with something elusive and ephemeral (STG30 112).

Ferris suggests that he wrote ‘‘Manifest Destiny’’ in response to an unvoiced challenge from the Iraqi poet Saadi Youssef. He comments:

I was reading Khaled Mattawa’s translation of Youssef’s poem “America, America” on the eve of the US invasion of Iraq. I had joined thousands in marching to the state capitol in Madison to tell the US government not to start another war, not to indulge the blood lust that we too often are pulled by. While reading Youssef’s poem I was struck by his embrace of my country and its ideals while not holding back for a moment from his clear-eyed critique of our failures to live up to those ideals. (Appendix 1 273)

“Manifest Destiny” exposes the fallacy of the American cultural belief in individuals achieving dominion of their own destiny. The poem’s title, “Manifest Destiny” for example, is an allusion to the frontier settler’s duty to expand the country from state to state. John O'Sullivan first used the term to promote the annexation of Texas, affirming “the right of our manifest destiny to overspread and to possess the whole of the continent which Providence has given us for the development of the great experiment of liberty” (1845). Just as the pioneers were urged to seek out new spaces in the American West during the 19th century, Ferris’s speaker urges disabled individuals to open up spaces to secure a new community in present day America. The symbolic “maw” or mouth represents America as a place without border an open gateway at the border crossing:

The maw of America is open,

friendly is our middle name,

the only thing we have to fear is fear itself.
We take care of our own. (STG29 82-85)

“MAW” refers to the “Museum of the American West,” a space which preserves cultural heritage and highlights the present relationships of First Nation descendants (STG29 82). Ferris highlights the gap between the experiences of Native Americans and prevailing characterisations of the American Dream; the colloquial phrase, “friendly is our middle name,” is juxtaposed with a possessive military and nationalistic stance: “We take care of our own” (STG29 82). The question of what constitutes our “own” emphasises the otherness of those who are not. As Kirby argues, it is irresponsible to build walls around ourselves that prevent the flexible negotiation of who belongs inside; we must not “reify the distinction between ‘inside’ and ‘outside’” through formulating a politics of exclusion; we cannot abandon either space but must continually traverse the difference (189). The appropriation of quotations and allusions which intersperse the narrative condenses the distance by incorporating a curated language and history to trouble perceived boundaries of inclusion and equality.

The speaker’s manifesto shifts the focus from the wider community to the personal needs of the individual. As E.J. Hobsbawm puts it, the nation is a “dual phenomenon, constructed essentially from above, but which cannot be understood unless also analysed from below, that is in terms of the assumptions, hopes, needs, longings and interests of ordinary people, which are not necessarily national and still less nationalist” (10). The narrator in “Manifest Destiny” distances himself from the inglorious memories of the past with the disrupting refrain “I must be something to see” as a suspended couplet abruptly announcing everyday actions of the present. (STG26 18). The sensory ways of knowing: “I see you, America,” “I hear you, America” “I smell you, America” are juxtaposed with the short emphatic sentence “Do I count?”(STG26-27 1-46) It is a pivotal moment emphasised by the enjambed space:

Just who is
your self, America? Do I
count? Three-fifths, say? I
am the crippled newsy on the corner,
the guy on the knuckleboard, not a leg
to stand on. Now I am the standard-bearer,
standing out not up. Stand by, America – (STG27 44-50)

At the forefront of Ferris’s questioning of nationhood, the narrator’s rhetorical question slips over enjambed lines and asks “Just who is/ your self, America?” (STG27 45-46). With an ambiguous positioning of “your self,” playing on the name Youssef, the narrator explores the central question of how the nation perceives itself: either containing a varied, imperfect spectrum of collected identities or a narrow elite of individuals who represent the conventionally accepted ideals of the nation. Manuel Castells observes that contemporary nationalisms tend to be “more cultural than political, and thus more oriented toward the defense of an already institutionalized culture than toward the construction or defense of a state” (33). Ferris remarks on the use of cultural tropes in “Manifest Destiny”:

I was also struck by his [Youssef’s] use of a refrain drawn from patriotic song, which led me to the idea of drawing upon American commonplaces, images and phrases so central to the American mythos that they would require no citation. (Appendix 1 273)

An example of this occurs with the enigmatic rhetorical phrase, “Do I/ count? Three-fifths, say?” referencing the racial demarcation of three fifths which was used in the past to discriminate against individuals who were not deemed sufficiently Caucasian (STG27 60-61). Ferris suggests that discourses of exclusion are highly pertinent now, and are always close to home. As he states in “Poet of Cripples,” we have to confront ourselves and “Look with care, look deep” within our own neighbourhood (HPix 12).
In the reflective space of Ferris’s poem, new representations of disabled nationhood emerge and contest the cultural signs, symbols and mediations of old narratives formulated from ableist perspectives. As Marion Quirici argues, “The disability justice paradigm therefore conceives human weakness and vulnerability not as an exceptional state that disrupts progress or burdens the economy, but as a structuring principle of a collective and interdependent society” (284). Ferris’s poems often express his desire to be part of the “whole” rather than a separate and distinct disabled-culture, or one reduced to a narrow spot. The speaker advocates expansion into new territories: “One small step one giant” (STG26 6-7). The anticipated concluding phrase “leap for mankind” of Neil Armstrong’s moon landing speech is omitted. It implies that future acts of agency must no longer reference the individualism of “one” but emanate from a collective enterprise for all humankind (STG26 6). Kuppers positions Ferris as a “resident” of a newly imagined land, a “disabled country”:

That land, disabled country, has many shapes, forces and myths— and the Greek myths are some of the building stones, some of the books, that those who claim disabled country can use. We can build contradictory homes, with different keys for different people, make people think of their limbs and their senses, their breath, as they enter our world. (“Disability Culture Poetry”) As a disabled person, Ferris is a member of an exclusive group of poets, academics and theorists, writing of “another land and language,” supporting the navigation of social organisation and spatial milieu (“Disability Culture Poetry”). Kuppers concludes that the dynamic interaction of crip poetry and crip culture can “open up layers of living” thereby enabling others to “see our world with different eyes” (“Sounds of the Bones”). The spatial boundaries between the “crip world” and non-crip “country” are blurred and/or collapsed (“Sounds of the Bones”). As Ferris concludes, this is an ongoing process:

I read that poem at a poetry reading at a university in the American South just a couple
weeks ago, and it still has power for me: at one point toward the end of the poem, I always feel like crying. Recognizing both our recurrent, deep, pervasive failures to live up to our ideals, while still asserting the hope in the ideals - that was the challenge from Youssef. Maybe someday I will get to show him the poem. (Appendix 1 273)

“Manifest Destiny” layers historical and contemporary cultural references to re-create a complex and alternative space of future hope. The poem allows a space in which multicultural and cross-temporal sources co-exist in order to communicate the richness of an inclusive land that accepts difference:

We are all your children, the atoms of your hope.

Let the better angels of our nature

form a more perfect union,

and let us be orphans no more. (STG30 122-125)

In this vision of the virtual space of the future, different voices intersect like messy, colliding “atoms” disrupting and dissolving previously mapped contours of difference (STG30 122). In fusing together each particle of “hope,” we learn from each other, from the past, and from the dispelling of unfound fears (STG30 122). The repetition of “let” claims a liberation from restraints, recalled associations and traces of memories (STG30 123-125). No longer “orphans” in this space of freedom, disabled citizens can find a future home (STG30 125).

“Slouching Towards Guantanamo” and “Manifest Destiny,” encapsulate Ferris’s aspiration to enlarge the sphere of possibilities “against which the imagined future world is formed” (McRuer 72). They consider what it might mean if we accept that there is no norm. Dolmage suggests that when “we broach such considerations, we feel a challenge to our own agency and autonomy, but we actually also gain perspective” and importantly, improve understanding of what it means to be human (849). McRuer goes beyond the statement that we are all cripples to suggest that we should “always comprehend disability otherwise and . . .
collectively, somehow access other worlds and futures” (208). Published five years after McRuer’s theorising on “other worlds,” Ferris’s poems are poetic representations of what that emergent space might look like (208).

**Conclusion: “People like you”**

Ferris crafts poetry that explores the relationship between institutional power, individual and collective identity and the concept of disabled citizenship. Space is at the forefront of his poetry through depiction of enclosed hospital spaces, movement between domestic and institutional settings to panoramic visions of the country as a whole. His poetry shifts in his writing from the claustrophobic interiors of hospitals in childhood to the imagining of alternative, inclusive spaces in his later work. Space, whether it is hospital buildings or whole imagined countries, is important in aesthetic and political terms, the representation of disabled individuals in public spaces validating the existence of individuals with non-normative bodies.

It is important to view that all individuals will encounter some form of disability whether it be caring for relatives or facing disabling illness at some point in their lives. Ferris comments on the need to recognise that disability is “ultimately uncontainable; it touches, perhaps even structures, every area of human experience” (“Review of Moolman”). He acknowledges the porous boundaries of disability as a constantly shifting category. His poems construct landscapes and reimagine dreams of a disabled country as a medium through which to explore and challenge contemporary societal fears and anxieties that needlessly divide communities. In re-writing and transforming space, these connections and shared values represent a fusion of cultural codes wherein individuals can be both disabled and American. As Kirby argues:

Space, then, seems to offer a medium for articulating - speaking and intertwining - the many facets, or phases, of subjectivity that have interested different kinds of theory:
national origin, geographic and territorial mobility (determined by class, gender, and race), bodily presence and limits, structures of consciousness, and ideological formations of belonging and exclusion. (174)

In this sense, Ferris’s poems become performative spaces which engage the reader in examining and reconstructing bodies, barriers and spaces. He is interested in points of intersection: How the social processes that create disability work, where they come from, and how they continue to impact the lives of disabled and nondisabled people alike - these are vital and complex questions. Attention to lived disability experience is vital to illuminate cultural beliefs and social practices that only show themselves clearly when disabled bodies bump up against them. (“In (Disability) Time”)

According to Ferris, certain attitudes only become visible when bodies come into contact. In seeking to “explore” these lived experiences, his poetry encapsulates the playful creative spatial experimentation advocated by Kuppers in her discussion on “transgressing” spatial and societal boundaries:

Equally experiential are other cultural ways of being in space, of being comfortable to step onto the grass, of getting one’s shoes potentially muddy, of transgressing boundaries, of leading or being led, of the effects of university hierarchies, of the mysteries of being other. (“Embodiment, Environment, Disability Culture” 5)

Poetry writing is a part of this process, as Amber Di Pietra notes, “Writing then, becomes a pre-emptive attempt to determine my angle of incidence. I do not act, but measure the contours of a form I might take” (273). Ferris’s poems “act” rather than “measure” and attempt creatively to fill gaps in current forms of representation by presenting the real life experience of transcending the institutional life of a hospital and finding a sense of self in the outside world of community. They also act as a heuristic lens through which he represents real and perceived limitations of American values. Whilst the Declaration of Independence proclaims that “all men are created equal, that they
are endowed by their Creator with certain unalienable Rights” (Kent et al.), Ferris’s later poems present an alternative, imagined space of equality and inclusion; a new collective space or nationhood of disabled dwellers.

Introduction: Seeing through “a series of veils”

Blindness is often perceived by the sighted as an either/or condition: one sees or does not see. But often a blind person experiences a series of veils: I stare at the world through smeared and broken windowpanes [sic] (Kuusisto P1).

This chapter explores American disability poet Stephen Kuusisto’s poetry, life writing, and critical articles on disability discourse. These take the form of online blogs, memoirs and conversations with me and others in the disabled community. The majority of poems analysed are from his debut collection Only Bread, Only Light (OB) (2000). Others like “Letters to Borges from London” and “The Books to Come” are from his second collection, Letters to Borges (LB16 10). As Carlos Reyes notes “These compelling self-portraits take us toward an understanding of the unfathomable condition of blindness. But, more importantly, they lead us to a superb poet” (“Poet”). In his blog “Planet of the Blind,” Kuusisto writes about disability from a socio-cultural perspective in order to critique the narrowness of societal attitudes. His poetry reflects similar thematic concerns relating to the visibility of his condition and his own intense awareness of how other people see him. As an academic, he teaches about issues of disability embodiment and perception in courses on disability, public policy, disability and history at Syracuse University (Chard de Niord 4037). He invites us to think about how poetry is a medium for re-appropriating ideas and language on blindness. He considers ways of re-orientating language and thinking, drawing on the diction and rhetoric of familiar literature, reconstructing uniquely subjective experiences to make conspicuous the linguistic frameworks that support societal oppression and social injustice.
Kuusisto also explores how poetry allows for ways of knowing the self to be re-examined using the various speakers to construct different experiences from multiple viewpoints. In “Letter to Borges from Buenos Aires” these alternative perspectives are juxtaposed in the opening stanzas: “Things are seen/ Through the eyes of girls –// Borges, tell them what you see” and the poem concludes with the climatic rhetorical question “Is this why you stayed home, /Behind a window” (LB12 1-21). Knowledge of the self, Kuusisto suggests, comes from the inside as a resistance to outside practices and stigma: “I think it’s fair to say the mind and body are not separate as we are customarily taught and I think this is particularly evident to anyone who must puzzle out the ways and means of living what is still often imagined as a spoiled or ruined identity” (“Crip Street”). Goffman’s concept of “spoiled” identities is alluded to here emphasising culturally imposed ideals of bodily difference (“Stigma and Social Identity”). Goffman argues, “By definition, we believe the person with a stigma is not quite human,” lacking and less than whole, adding, “We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences” (5). Goffman’s words recall Ferris’s comments on disabled individuals representing a “danger to the normate world” and are indicative of stereotypical attitudes that marginalise blindness as “ruined,” inferior and other (Ferris “Disability and Poetry” 272).

Kuusisto’s poems, I argue, represent atypical perceptions of embodiment and challenge stereotypical representations of blindness through the lens of space. He asks us to reconsider how the experience of space, the negotiation and perception of relational objects in space and ocularcentric philosophical notions of what space is might be interpreted and imagined differently by someone who cannot see. He argues that his poetry is not concerned with exactitude:

Poets aren’t journalists, and those poets who have studied Dada and Surrealism aren’t concerned with Pound’s “Imagism”—we’re not trying to create a photographic image in
poetry. And that’s a liberating sequence of ideas especially if you can’t see the world like a
Life magazine photographer. (“Lyric Anger” 196)

Kuusisto situates his work outside the field of Ezra Pound’s “Imagism” which is characterised by a
clarity of language that “rendered meanings in precise detail” (John Maerhofer 97). He avoids
being constrained by any requirement to provide literal, ocularcentric representations of physical
space; instead, he embraces an impressionistic, abstract style.

The deficit model of blindness is inverted in Kuusisto’s writing, crippled from a disability
perspective to undermine conventional ocular motifs and symbolism. Kuusisto’s metaphor of
“smeared and broken windowpanes” from his memoir Planet of the Blind, is a playful
representation of his subjective experience of embodiment, his subversion of dominant
ocularcentric discourse and his perceived aesthetic role as a poet (1). Windows are architectural
features that represent a boundary between inside and outside, subject and object, open and closed.
For Kuusisto, these apparently binary oppositions are indistinct and the perceptual distance
between relational objects is blurred. This is represented in both literal and metaphorical senses
through the frequent inclusion of spectacles, kaleidoscopes and camera lenses in his poetry. To
access public spaces, the speakers identify as blind making the condition visible. In fact, whilst the
glass surface acts as a physical but transparent barrier protecting the interior psyche from outside
forces, the shielded speakers are simultaneously enclosed and psychologically exposed. They are
visible to those outside the window, an inferior being on show as a curiosity imprisoned by panels
of glass.

Kuusisto’s metaphorical lens is “smeared” suggesting the parameters of language and
poetic consciousness are deliberately less defined. The lens is also “broken” suggesting an attempt
to break from the limits of language. Beyond the window boundary lies the unseen, the “unknown
becomes more fascinating and attractive than the known” (Bechir Kenzani 42). In the poem
“Dante’s Paradiso Read Poorly in Braille” the space beyond the window is obscured:
Finger reading,
A tempered exercise,
I notice how dark
The window has become (OB12 21-26)

For Kuusisto, the space beyond is an unexplored frontier, a horizon opening out into an infinity of indistinct possibilities and points of contact with other attitudes and ideas. Like reading opening up worlds, the window metaphor is also figured as an opening that gives access to hidden meanings, mysteries that are revealed only through the imagination of the poet. Kenzani comments: “Behind this blurred window . . . stands a world, which the creative power of the poet is going to make visible and true” (42). For Kuusisto, poems are the medium to make the hidden visible and muted voices heard. In a blog entry, Kuusisto articulates how it feels to be both on the outside looking in and on the inside looking out:

Like the marks of children’s fingers on the glass, disability is at the window. Like those tiny, smudgy marks we don’t like this disability thing. No one likes it whether you’re inside looking out or outside looking in. No one likes it. Even those of us who seek to celebrate disability culture are invariably struggling with the relative disinterest of “abled” culture, whatever that is. If you have a disability and you love the arts you can often feel like the person inside who looks out the window. In this figure the “outside” people are looking in, where they see the disabled trapped in their little glass room of performance. This is a hard figurative position to escape. No one wants to be side-show entertainment.

Or, by turns, from a position of political persistence and some authentic naughtiness, some of us relish the opportunity to be poetry cripples. If we’re “inside” the room and standing at the window we hold up a mirror and by turns, if we’re outside and looking in, well, we hold up a mirror. (“Disability at the Window”)

If disability is positioned “at” the window, then it is visible; the simile of the “fingers” marking the surface indicates that disability is normal and touches everyone (“Disability at the Window”). But society resists claiming the disabled, dismissing them as nameless “things”; they remain outsiders, yet “trapped in their little glass room,” ignored and oppressed by societal attitudes (“Disability at the Window”). Like Ferris, Kuusisto interrogates his spatial position in the material world and uses poetry to reshape the contours of his body and his identity in order to challenge fixed ideals about normality and embodiment.

Kuusisto’s poems are figurative windows giving insight into oppressive policies and practices from the inside. When Kuusisto positions himself as part of a community of “poetry cripples,” he suggests that these writers produce work because “We want the ‘normates’ to see themselves seeing us” (“Disability at the Window”). In this sense, it is clear that he intends his poetry to function, at least in part, as a form of activism, demystifying visual impairment. In “Letter to Borges from Galway” the speaker asserts:

I am not unique.
I stand beneath the shutter and weep.
I love this world.
I am alone in a new city.
If I died here beside the river and the window,
Maybe everything I’ve known
would make sense in the gray of an Irish minute. (LB15 7-13)

The repetitious “I” and emphatic end stopped lines shift to softer enjambed lines with the word “Maybe” expressing hope for future understanding (LB15 12). Kuusisto’s desire to rewrite blindness and to complicate acts of looking connects to David Bolt’s challenge to the “metanarrative” of blindness: “the story in relation to which those of us who have visual impairments often find ourselves defined, an overriding narrative that seems to displace agency”
(The Metanarratives of Blindness 10). Kuusisto’s poems, I argue, insist on reclaiming this “displaced agency,” presenting a cripped alternative to ocularcentric notions of embodiment through the re-writing and re-imagining of space (Bolt 10).

Kuusisto’s poems examine the constructed nature of embodiment and in particular, challenge ideas of “normalcy” as it relates to discrimination and labeling of blindness as an abnormal state of being (Davis “Crip Strikes Back” 504). They call attention to external surfaces of bodies, relational objects and spaces where “normates,” to use Garland-Thomson’s term, define vision in ocularcentric terms (Extraordinary Bodies 8). Rod Michalko comments on blind embodiment and the experience of stigma and exclusion:

The ‘world of the normal,’ that is where I become blind, that is where I am blind. Even though such a world is not an obviously empirical one and thus is one constructed out of particular interests and values, it is the world in which I live. The ‘world of the normal’ is the background against which stands the figure of blindness. (38)

Kuusisto poetry helps us to imagine a larger picture, seeing through different eyes, giving insight and multiple perspectives on embodiment. They expose what the sighted amongst us can sometimes fail to see: we often overlook the disenfranchisement, marginalisation and societal practices that denigrate others. In western ocularcentric culture, Clinton Sanders notes, blindness is “regarded as having a significant impact on identity” and sense of self (133). In addition, blind individuals are often ignored by members of the public who are made “uncomfortable by their stigma” (Sanders 133).

Kuusisto’s poems, I contend, also act as mirrors in that they reverse the expected image and show an inverted reality. Christopher Jones notes that “When we look at ourselves in a mirror, our gaze is returned by the very gaze that looks. We watch ourselves watching ourselves” (“Symbols In Art”). Kuusisto refers to his unique perception of external or abstract objects as “double seeing,” a type of surreal “deep image” made from associative leaps that “create an
interior sense of emotion and fraction and comprehension” (Niord4109, 4106). Like Ferris’s “cultural storehouse,” Kuusisto’s interior space of the imagination connects diverse emotions and experiences, forming alternative perspectives from the inside (Appendix 1 271). Diego Báez observes that “the brilliance of [Kuusisto’s] verse acquires deeper resonance, for his work imagines a realm between sight and sound composed of the sensory stimuli we all know and recognize, but split, fractured, and juxtaposed to inhabit the mind’s ear of his readers, a feat unique to this truly gifted poet” (“Poet”). Kuusisto’s poems explore how sensory perceptions intersect in order to stimulate fresh ways of seeing and thinking. He describes this use of poetry as a space in which to connect and give form to these associative leaps:

‘Association’ in surrealism means putting things side by side that don’t belong together logically — ‘the sewing machine on the operating table’. . . poetry raises this quality of the illogical to a higher level by insisting that there are states of mind, of perception really, that can’t be represented by stable, figurative imagery ("Lyric Anger" 196).

The emotive quality of these highly visual scenes remind us that “People do not only structure place and space in different ways, they also experience them differently” (Cecilie Høj Anvik 146). Anvik adds that whilst “blind embodied spaces” underline the “activities and bodily experiences we all share,” Kuusisto’s poems have a capacity to elucidate the dominance of “other bodily senses we use when interacting with our environment in constructing our bodily spaces” (146). Poetry enables Kuusisto to achieve this because it is a “portal to the intricacies and beauties of the inner life” (Niord4012). The poem “Serenade” is about the childhood experience of being outside, lost in thought and at one with nature. It is indicative of Kuusisto’s surreal imaginaries of distance, flight and escape from the painful reminders of everyday reality:

When the birds came
He rose through the tatter of clouds.

The boy with two faces, he flew through clouds.
The kid who couldn’t see, he flew right up.

His parents came, they banged on pots and pans;

They hoped to get him back to earth.

But they were far below,

And the boy was in the sky of verities. (OB15-16 19-26)

From the boy’s vantage point, letting go of earthly ties enables him to inhabit the “sky of verities” surrounded by higher truths and values that sustain him (OB15 26). The distance between the self and the world opens the space for non-correlation.

As portals, his poems allow for a creative movement between interior spaces of the mind and the spaces of the public sphere. Unfamiliar spaces are accessed and otherwise inaccessible spaces are read and re-interpreted. Reading spaces, Joshua Inwood argues, is a sensory mode of explication and navigation:

The blind read the world as a text creating an image of the world that is different from the sighted. Just as we read a book and construct a mental image of the landscape from the words and meanings behind those words, the blind also “read” the environment. The senses which they utilize - touch, taste, sound and smell - form their own words to construct a mental image of a landscape. (42)

The world is deciphered as a “text,” its language decoded and its spaces reconstructed. Its raw material is reshaped into a mental image which is differently configured from a sighted person’s perception. Kuusisto’s spatial landscapes are constructed, I argue, through the perceptual lens of “glacial seeing” a term coined by Kuusisto himself to define his subjective reading of space as an abstract mode of perception:

It’s like living inside an immense abstract painting. Jackson Pollock’s drip canvas Blue Poles comes to mind, a tidal wash, an enormous, animate cloud filled with light. This is
glacial seeing, like lying on your back in an ice cave and staring up at the cobalt sun. The beauty is of course conditional. (P7)

These comments emphasise sensory discordance and visual distortion since abstract art places emphasis on promoting the relationship between entities rather than their representation as recognisable objects. Kuusisto’s subjective way of seeing, D.W. Meinig argues, occurs naturally, as different people exposed to the same prospect “will not – cannot – see the same landscape” (4).

Born legally blind, with a condition that causes his eyes to move erratically without his control, Kuusisto’s poems communicate the blurred, fractured shapes that form ambiguous depths and shadows between inverted realities. He comments:

By the time I discovered poetry… a kind of wonderful connection happened between that early foregrounding of the inner life and the discovery that Auden called ‘the cave making’... it gave me a corridor to very powerful places that were already constructed - a kind of rich and unaffiliated place in my head (Niord4011)

Kuusisto connects W.H. Auden’s “cave” in “The Cave of Making” with an “ice cave” of his own making in a poem of the same name:

Here’s to the cave of making
where the lonely write their poems,
where kings and queens have foundered
and no one has a phone.

I went there as a child,
a blind little kid
and drew pictures in a scrap book
just as Jesus did.
The walls of the cave are narrow
they’re neither light nor dark,
you may write whatever you wish
with a tiny dot of chalk.

The cave has nothing festive
no promises or lovers;
On its floor are the seeds of memory
and match book covers.

No one else will visit
so plant an abiding staff
where the light is inconsistent
and your heart is sharp as a gaff. (lines 1-24)

The alternating rhyme scheme creates a well-ordered, witty, private sphere of a mental space
where “No one else will visit” (21). Its chatty colloquial style claims a liberation from past ideas
and events as “scrap book” memories lie discarded on the “floor” (7-15). The freedom in being
able to “write whatever you wish” is contrasted with the ephemeral nature of “chalk” (11-12). To
effect a revision of acquired habits requires a more robust literary marker. In Auden’s version, the
cave represents the mind as a place where language “projects ideas from the house of the mind
onto the outside world, in the process creating a fully human landscape charged everywhere with
spiritual significance” (Stan Smith 211). For Kuusisto, the cave-making space of the imagination,
signifies the power of poetry to plant an “abiding staff” which de-familiarises and makes oblique
connections challenging the relation of things spiritual, abstract and material (22). He notes:
I’m not writing prose that’s powered by the appearance of truth (‘verisimilitude’ is what Henry James called it). I am driven by the vagaries of poetry and the imagery in my prose is entirely unreliable though it feels clear for all that. (“Digressions on Poetry” 198)

Plato’s discourse, *The Republic*, remarks on the problem of gazing at reality for the first time: the individual is “too dazzled to be capable of making out the objects whose shadows he’d formerly be looking at” (241). Whereas Plato’s imprisoned figures imagine they see reality and are content, Kuusisto’s speaker repeatedly questions the intelligibility of the shadows and calls attention to the ambiguity of thresholds between what is real and what is imagined.

Through this interior landscape, Kuusisto interrogates societal attitudes to embodiment, blindness, stigma and the language of prejudice. His writing resists ocular motifs of seeing that erase the interior sense of self and represent blindness as “synonymous with ignorance” (Bolt “Aesthetic Blindness” 93). Penelope Scambly Schott observes that Kuusisto’s prose memoir, *Planet of the Blind* (1998), “is literally about seeing —and not seeing” (“Review of Planet of the Blind” 218). Kuusisto’s writings contrast predominantly “sighted” theoretical discussions of ontological concepts that equate “seeing” with “knowing” outlined by critics such as Suzanne Akbari (158). As self-critical examinations of embodiment, Kuusisto creatively obscures meaning and presents a chiaroscuro landscape of shadows and inversions, such as in his poem “Nones,” which says, “I ate of the shadow, the shadow/ Ate of me” (*OB*98 1-2). The image of shadows devouring themselves suggests how external objects become incorporated into his interior imaginative world.

For Kuusisto, past and present, real and imaginary worlds are recreated simultaneously through interlinked sense-impressions in the space and time of the poem. Kuusisto invites readers to “stare at the world” and to accompany him on the journey; to reconsider the primacy of vision as the “ideal perspective for interrogating and arriving at phenomenological truth” and to challenge the prevalence of “ocularcentric bias” (Jesse Workman 133). As Dvora Yanow observes,
writing space gives authors a degree of agency; it moves them “from a passive-reactive role in which they or their behaviours are seen only as being shaped by the space” (373). Through his writing and imagination, Kuusisto reimagines space to resist being shaped by space; he describes a world he cannot see and a society that appears not to see him.

Many of Kuusisto’s early poems feature representations of living inside enclosed spaces, looking outward from the edges but also of using his imagination to inhabit different planes of existence in space and time. Section One of this chapter, “Enclosed Spaces: Visibility and ‘Hurtling’ through Spaces,” analyses the poems “Awake All Night,” “Terra Incognita” and “No Name for It.” These four poems are from the introductory section to “Part One” of Kuusisto’s four-part collection, Only Bread, Only Light. They are linked by their focus on childhood and grouped under the heading “Blind Days in Early Youth.” They communicate the experience of being marginalised, the emotional detachment and psychological exposure to ridicule. They situate events in the private spaces of the home, in the sheltered landscape of the garden, the bedroom and the attic. In the poem “In The Attic,” for example, the speaker retreats to the confined space of the attic and listens to familiar music:

The radio vibrates imperceptibly;
I’d forgotten it was on
And turn the volume up – but slowly.

_Bach: ‘Invention no. 13’ . . . (OB35 1-4)_

From the space of isolation comes a sense of familiarity and security: the spaces are closeted rooms and confined domestic areas, away from the verbal taunts of bullies, protected and surrounded by comforting sounds. These spaces are mediated through physical lenses of spectacles, telescopes, and panes of glass.

In other poems, young adult speakers transition to interstitial spaces which shift unexpectedly between public and private landscapes blurring the contour between real and
imagined spaces: urban cityscapes are reconfigured in the imagination as interior spaces of retreat. The sounds of nature blend with the sounds of city life. A sense of reclaimed agency comes from spaces re-conceived as liminal, the imagined narrators inhabiting an interstitial space positioned between sighted and blind, dis/abled worlds: “Crip Street is a dance floor. It’s liminal space. It’s both inside and outside our customary public square. That’s not an easy concept— in fact, it sounds petulant, as if I said, ‘I’m your neighbor sometimes, and sometimes I am not’” (“Crip Street”). The notion of strangers located within neighbourhood communities is found in the poem “Accomplice”:

Perpetual strangers

Touch my sleeves,

The steel light of August

Draws me, affirming

Over brilliant and terrible streets, (OB 10 1-8)

Kuusisto juxtaposes the physical and sensory contact of “sleeves” touching with the phrase “Perpetual strangers” to signify reality as an absence of emotional and intellectual contact (OB10 1). In contrast to the emotional pain of those who ignore his presence, the dazzling August sunshine and unfamiliar streets warm and entreat. His poetry re-imagines spaces where the disability community connects and crips representations of cultural customs and societal boundaries that make “strangers” of others through encounters of difference and “(mis)recognition” (Ahmed Strange Encounters 32).

In Section Two of this chapter, “Transitory Spaces: Audible Soundscapes and Accessed Worlds,” the poems “Guess,” “Post–Orphic” and “Learning Braille at Thirty-Nine,” emphasise the different ways the speakers navigate environments and encode spatial and social information. Using a visual frame of reference to orient the body in space, these poems also relate experiences
based on the reception of “enhanced auditory processing” and sensory touch (Monica Gori et al. 319). R Murray Schafer first coined the term “soundscape” in 1976, applying it to the plethora of noise and sounds that combine to demarcate acoustically varied “sonic” environments of the industrial revolution (71). The term “soundscape” is derived from “landscape” and can be defined as the auditory environment within which a listener is immersed. According to Bryan Pijanowski, these soundscapes are encoded from the “collection of biological, geophysical and anthropogenic sounds that emanate from a landscape” (1214).

Kuusisto’s soundscapes in “Guess” and “Post–Orphic,” evolve in the spaces of nature and on the fertile grounds of the imagination: Arcadian and Eden-like havens of protection and nurture. Concepts of nurture and social production of space as a communal and literary process are exemplified in the poem “In Our Time” where bees, emblematic of regenerative activity, are part of an anticipatory process:

I remain motionless

Like Thomas Traherne

And listen for the bees

From the estate of innocence.

In the thick shade

The maple seeds

Rise like sparks

Just out of reach. (*OB55* 28-35)

An image of prelapsarian childhood consciousness suggests that experience diverts from the insight of intuition. The speaker is “motionless” listening to industrious “bees” in an Arcadian-like “estate of innocence,” a stasis of purity like Adam before eating the apple (*OB55* 28-31). They lie
hidden in the protective darkness of the “shade,” yet the “seeds” from the maple fly above like expansive inspirational “sparks” (OB55 34). These “sparks” are tantalisingly out of reach so, in the meantime, he gathers “twigs,” collecting branches on which to graft other people’s thoughts (OB55 39). The verse indicates ideas need room to grow, overlapping through time to ripen in productive ways but this growth is thwarted by unseen external forces. Thoughts are contained by “thick shade,” a barrier that hovers between light and dark resisting sensory definition of form (OB55 32). Kuusisto figures the shadow boundary metaphorically to suggest the lack of liberation, the false transparency and illusory nature of lived reality (P1).

Within this metaphorical inner space of the mind, the speaker explores what his senses intuit from experiencing the landscape around him. His poetry “explores the bodily senses in a myriad of ways, investigating how sight, hearing, and touch serve to facilitate expression and communication by both receiving information and transmitting information” (Michael Melancon 184). Touching objects and running fingers over books written in Braille highlights the material nature of reading itself. Kuusisto experiments with the demarcation of material and imagined spaces to unsettle conventional thinking about power and space, bodies accessing space differently and how cultural representations of space define embodiment:

Crip Street is a place in the mind. Living there I understand that not all the gates are open to my able bodied friends. When I understand this I begin to experience the power of my alterity. We Crip people are beginning to live the Eleusinian mysteries of our differences. And we will let you in from time to time. But not always. (“Crip Street”).

Examples of this synthesis of verisimilitude and myth within the mind is prevalent where Kuusisto re-imagines spaces of sanctuary, productivity and community as gardens, libraries, and cities of beehives. Seed, grain and fruit metaphors are employed alongside the conceit of books and bees to represent the cross-pollination of ideas essential for an organic growth in language and thinking.
Kuusisto’s later works, I argue, expand outwards to encompass unfamiliar continental terrains, ambiguous spaces reconfigured as expansive landscapes which merge myth, dream and reality. They are situated in contexts which then question perception of the intelligible world, the appearance of phenomena and the presence/absence of sensible knowledge. In these surrealist dreamscapes, time and space slip between realities to expand the potentiality and intersectionality of cultural habits and linguistic practices. In the frontispiece to *Letters to Borges*, Kuusisto cites Yehuda Amichai to emphasise the interrelated part we all play on the worldwide stage of interconnected lives:

we will appear, like wandering actors

each in the other’s dreams

and in the dreams of strangers whom we didn’t know together” (*LB*vii).

Performance through poetry connects the “dreams of strangers,” condenses the distance between those “whom we didn’t know” and unites us “together” (*LB*vii). Kuusisto explores relationships between lived experience, cultural representations and dominant discourses on blindness to suggest alternative perspectives on embodiment. Just as Ferris crips notions of hope in his representations of the ‘American Dream,’ Kuusisto suggests that conventional notions of social justice, universal equality and accessible spaces are illusory fictions. Expressing these relational differences of real and imagined consciousness, he explores what it means to be blind, subverting ableist perspectives and prejudices by imagining new realms where all are equal, all are blind, and all are disabled.

In Section Three of this chapter, “Transgressing Terra Incognita,” the poems “Guiding Eyes,” “Letter to Borges from London” and “The Books to Come” turn outwards, moving away from the domestic spaces of his poems about childhood towards adulthood and travel. They communicate a sense of freedom in negotiating both real and imagined spaces. These poems are interested in capturing the experience of moving as a body in space and finding a sense of self
within those spaces. In “Guiding Eyes,” the speaker negotiates city spaces, mapping unfamiliar locations and gaining access to urban American and continental cityscapes. For Kuusisto, more spaces become accessible because he obtains a guide dog. He represents this newfound freedom through the outlook of speakers who negotiate space in new ways with an accompanying dog; he explores the sense of external protection associated with being with and alongside a significant other (for example, the guide dog Corky in Kuusisto’s memoir). “Letter to Borges from London” and “The Books to Come” also explore how non-fiction books of science, geography and travel literature, for example, allow us to connect with epistemological truths about bodies negotiating the real world. Fiction, in Helen Keller’s words, opens up interior spaces: “Literature is my utopia. Here I am not disenfranchised. No barrier of the senses shuts me out from the sweet, gracious discourses of my book-friends” (85).

In all three sections of this chapter, I argue that these past and present, real and imaginary worlds are layered and connected through Kuusisto’s poetry. He uses the space of the poem to record and re-imagine various sense-impressions through a poetic synthesis of literary antecedents, fragments, allusions and testimonies, sounds and conversations. This literary consciousness in Kuusisto’s poetry is, I argue, formed from the layering of unexpected images and linguistic combinations, creating a “crystallography of sharpened syntax” (P71). His poems explore encounters with objects and spaces in ways which distort and de-familiarise conventional philosophical debates and reject the “either/ or,” absence/presence binary of blindness. Kuusisto claims that “Poetry is only concerned with a provisional kind of truth” (“Digressions on Poetry” 198). His poetry, I propose, does not aim to replicate reality. Instead, it questions what happens when the visual lens is “smeared” or “broken” (P1). It enables us to reconsider how experiences of embodied blindness might be perceived from a disability perspective.
Section One: Visibility and “Hurtling” through Spaces

The poems, “Awake All Night,” “Terra Incognita” and “No Name for It,” are all representations of a childhood spent hiding disability within private, domestic spaces. “Awake All Night” explores an understanding of the external world mediated through a process of listening and seeing from the interior space of the attic. “Terra Incognita” is located in the enclosed outside space of the backyard. “No Name for It” situates the speaker in the stairwell of his family’s parental apartment and probes the limits of language that define blindness.

Encouraged by his parents, who lacked the “emotional language” to deal with his condition, Kuusisto not only “thrived on suborning his blindness” until he sought special assistance at the age of thirty-nine, but resisted being seen as blind by others (Fletcher “Steven Kuusisto” 615). To convey his resistance to being both hypervisible (seen as blind by others) and made to feel societally invisible (socially alienated by prejudice), Kuusisto adopts the term “outlier,” made popular by Malcolm Gladwell (Niord3397). Gladwell’s term expresses “something that is situated away from or classed differently from a main or related body” (Outliers: The Story of Success 3). The sentiment echoes Kuppers’s description of disabled individuals as being “marginalised and invisible - relegated to borderlands, far outside the central area of cultural activity, into the discourses of medicine, therapy and victimhood” (Deconstructing Image: Performing Disability 25). Kuusisto’s numerous stays in hospital make him resistant to the idea of medical intervention; although he retreats inwardly, he avoids projecting himself outwardly as a victim. As a child, he felt “a sense of ostracism and loneliness” and his space narrowed (Niord3998). It became an “isolated and rather beautiful, but very private, kind of experience . . . I had a very, very intense kind of inner life, and that inner life is a thing . . . of the wonder and strangeness of being alive” (Niord3997). At other times, in order to achieve the outward appearance of inclusion amongst his peers, Kuusisto recounts his attempts at learning and
navigating space by memory and sound, often at speed, resulting in numerous near-death injuries which reinforced his sense of failure.

Kuusisto draws on these autobiographical experiences, mediating them through the speaker in “Awake All Night,” “Terra Incognita” and “No Name for It.” The poems raise questions about how blindness is perceived by others but also how blindness is addressed by those who are disabled. They foreground space as a conceptual framework for understanding and experiencing the world, as well as writing about it. They explore the visual, auditory and haptic relations between different spaces and reconfigure conceptions about the continuity of spatial arrangement. Discussing meanings of blindness across cultures and history, Julia Miele Rodas touches on Kuusisto’s description of “the relationship between volition and identity,” indicating that because he is between seeing and full blindness, “categorical characteristics are indefinite, the choice of identity—blind or sighted—can become a matter of will” (119). The poems give an insight into how Kuusisto perceives himself as an “amphibious” figure situated between the world of the blind and the sighted, a lived reality that it is not an either/or state of being (P22). Like Ferris, Kuusisto reflects inwardly and attempts to grasp the whole through a process of looking and listening, which includes exploring his interiority and personal distinctiveness. His poems articulate how living in the world, perceiving the world and other objects, is a matter of the whole body, not a dominant single sense. They are about feeling at once separated from and exposed in the environments that he inhabits.

Kuusisto’s poem “Awake All Night” represents an attic space through an unpredictable assemblage of thoughts, sounds, and tactile impressions. “Awake All Night” illustrates the complex ways we understand the world and crips conventional notions on sensomatic perception. As Teresa De Lauretis observes, Kuusisto captures the minute details in order to present the “blind spots, the spaces off… not visible in the frame” (26). The poem re-imagines these blind spots as spaces that exist beyond the physical barrier of the radio dial and optic
lenses. Paradoxically, external sounds enter the space and the unseen is made momentarily visible. The radio “glows” as if sentient, its channels activated. Objects and sounds emanating from and existing within the “city of tubes” come momentarily into focus, into being. The everyday experience of listening to the radio is seen to be a moment filled with wonder; the magical “brilliant” radio transforms the ordinary into the extraordinary. The synergy of the visual, tactile, and auditory senses emerge:

The cabinet radio glowed
With its lightened dial

As I pressed my face to the glass.
My spectacles, thick as dishes,

Were kaleidoscopes of light,
So I’d lean close

To make out numbers,
And the brilliant city of tubes

Just visible through a crevice.
I never heard the music

As I traced the lamp-lit houses
Like a sleepy, mindful ghost

Who looks down out of habit
At the vivid world. (OB7 1-14)

The image of lenses as “thick as dishes” mocks the prejudice and puerile preoccupation with outward appearances. It is appropriated from Kuusisto’s memoir in which he describes how “Under the violet streetlights my glasses, thick as dishes, fill with aberrations at the edges of their thick curves” (P66). Heather Yeung notes that it is “peripheral vision, rather than directly (self) focused sight that leads to the creation of a sense of surrounding environment” (91). In “Awake All Night,” the peripheral signifies distortion at the spaces “just visible” beyond the surrounding environment of the attic cave (OB7 9). Knowledge is found at the edges of experience and is elusive. Whilst the speaker might sense his surrounding environment, he cannot physically make contact with it; he peers through the “crevice” but like Plato’s shadow men, fails to assimilate the “vivid world” outside (OB7 14). The “crevice” as boundary, emphasises the sense of otherness: situated in the contained space of the attic, only the mind is free (OB7 9). The sounds “never heard” remain illusory, closed off, and hidden within the “lamp-lit houses” of the imagined cityscape (OB7 10-11).

Kuusisto makes an explicit reference to this sense of isolation, remarking: “I watch the spirals of hypnotic light that ripple across my eyes when I move them from side to side. I do not belong here” (P20). He comments on the psychological process of “hardening” as a means of self-protection: “I stayed alone in rooms, listening as a daily ritual, hardening my memory, making my tongue sharp” (40). In “Awake All Night,” however, the speaker’s thoughts traverse an imagined terrain and wander like a spirit ghost which “looks down out of habit” (OB7 13). His physical body remains in the contained space whilst the “crevice” marks the liminal border between representation and reality; once the outside is glimpsed, the potential for the mind to meet the world expands (OB7 9)).

Like the metaphor of windows, the motif of glass “spectacles” is a representation of Kuusisto’s embodied perception. It also expresses the experience of hours spent “peering into the
twilight through the dirty windows of my hopeless glasses” (39-40). The optic lens is “dirty” and, paradoxically, a cause of clarity and confusion. As Jonathan Crary notes, the kaleidoscope trope similarly exemplifies a “dissolving and reorganising of the world” where each turn of the lens disrupts (354). This representation of space as an unstable dynamic is indicated when Kuusisto states: “I see like a person who looks through a kaleidoscope, my impressions of the world are at once beautiful and largely useless” (P13). His “beautiful” yet blurred vision is impressionistic, ambiguous and uncertain. He makes us rethink how we understand things we have never seen; how we understand the meaning of different sounds, and how sounds are to be interpreted when the objects they originate from are themselves a mystery.

Kuusisto represents the properties of objects and their relation to other objects as unstable and illusory. Alex Lemon expresses a similar point: “Without sight, I felt the world had become an unknowable place. But the idea that I knew the world because I could see it was an illusion—an illusion of control” (167). The kaleidoscope lens fractures images, shifts light to dark and makes space depth ambiguous. For Kuusisto, it is also a signifier for diversity and community, emblematic of the universality of all shades of disabilities. This is evident in the nomenclature for “Kaleidoscope Connections LLC,” a charity organisation he established to raise awareness on diversity issues. The trope cultivates the idea of embodiment as a synergy of thoughts, sounds, emotions and tactile impressions, offering infinite possibilities. It also suggests their transience. R.S. Dement recalls the moment he discovered that David Brewster’s 1817 patented invention is nothing but “numerous pieces of colored glass,” its beauty of symmetry “only a delusion” that tricks the eye (Jason Farman).

For Kuusisto, the clarity of knowing is illusory, intermittent and fleeting. Moments of revelation are “alternatively prismatic, then dark as a jail” (P67). They are equated with miraculous instances, “a terrible glittering, a requiem light,” a type of crazed euphoria (P8).
Objects magically appear or disappear as shadows form the layers of space which Kuusisto learns to negotiate:

The sensorium of the blind who possess some marginal vision is by turns magical and disturbing. There is nothing in front of you, nothing behind. Now there is a shadow in the shape of a man who has appeared from the mist. How lovely and terrible this is! It’s a mad, holy vision, the repeated appearance and disappearance of the physical world (P6-7).

The experience of blindness is expressed here as a “mad holy vision.” Helen Groth relates Byron’s “celestial kaleidoscope” in “Don Juan” to a similarly “prophetic vision of hope and natural beauty that borders on the sublime” (221-222). In “Awake All Night,” the child speaker lies awake and presses his “face to the glass” (OB7 3). The allusion to 1 Corinthians 13:12 “For now we see through a glass, darkly; but then face to face” emphasises the inexperience and the paucity of his language to communicate what lies beyond his reach. George Herbert’s poem “The Windows,” expresses a similar thematic concern:

He is a brittle crazy glass;

Yet in thy temple thou dost him afford

This glorious and transcendent place,

To be a window, through thy grace. (The Temple 61 2-5)

Like Herbert, Kuusisto endeavours to make the “temple,” the metaphorical “body of his poems,” a “window” through which he communicates embodiment (Mark Eaton 5-6). As Herbert reflects on humankind’s flawed nature and inadequate language, Kuusisto similarly explores our inability to harmonise external reality with a concomitant inner knowledge. Kuusisto’s poems capture this desire to dwell in a “glorious and transcendent place” of his own making and in the mind’s articulation of it (The Temple 61 4).

Like “Awake All Night,” the poem “Terra Incognita,” is situated in the protective space of home. This poem, however, marks the boundary between the end of childhood and the beginning
of adolescence. The speaker tentatively crosses the threshold of the known to enter the unfamiliar space of the outside. Within the security of the backyard, they explore the space of the garden which extends like an unknown continent. The Latin translation of the title “land unknown” is a universal cartographical term used to indicate unexplored regions and undocumented areas of space. Venturing into unknown space represents, for Kuusisto, a duality of loss and gain. It serves as a site of memory of both past and present. Inhabiting the exterior space paradoxically allows connection with interior spaces of the imagination. Bachelard suggests that the “house is one of the greatest powers of integration for the thoughts, memories and dreams of mankind” (Poetics of Space 6). Sounds disrupt the spaces of perception:

   When I walked in the yard
   Before sunrise,
   I made my way among patches of dew–
   Those constellations on the darkened grass.
   The webs drifted like anemones,
   And I thought of lifting them
   As if they were skeins of brilliant yarn
   That I could give to my mother
   Who’d keep them
   Until we knew what to make.

   I pictured a shirt -
   How I’d pull it over my head
   And vanish in the sudden light. (OB6 1-13)

In the liminal space of pre-dawn, the emergent light of sunrise typically replaces the darkness of night. In this confined landscape of the contained yard, the moment between wakefulness and
sleep remains shrouded in darkness. The speaker walks on “darkened grass” as if traversing space in a surreal dreamscape. The darkness is ambiguous; it both obscures and reveals. Dawn metaphorically marks the dissolving boundary between representation and reality, between abstractions and experience and signposts the flux of emergent and relational intensities between objects. Brian Teare’s comments emphasise this instability of embodied experience: “I have to write from a place of uncertainty and flux, despite my deepest desire for certainty and stability, because the nature of things both — interior and exterior — is transience” (185).

In “Terra Incognita,” the transient natural setting is permeated with a sense of fantasy and a mixture of expectation and trepidation. The “patches of dew” are described figuratively as “constellations,” astronomical symbols synonymous with the workings of bright stars. Nelson Goodman notes that constellations are patterns of lines connecting certain stars, “drawing certain boundaries rather than others” (36). These boundaries mark connections to create a map of the sky. Stephen Levinson observes that just as maps “stand in abstract spatial relation to real spatial terrain, so spatial relations can give us symbolic ‘maps’ to other domains [. . . in] the extended symbolic world that human beings inhabit” (357). Kuusisto imaginatively fashions his own “symbolic maps” as poetic representations of atypical embodiment in an inverted conception of reality. This abstract refashioning of space blurs the division between physical, mental and social spaces. It mirrors what Lefebvre terms “representational space” as space appropriated and reconfigured by the subjective imagination:

Representational spaces: spaces as directly lived through its associated images and symbols and hence the space of ‘inhabitants’ and ‘users’ . . . who aspire to do no more than describe. This is the dominated — and hence passively experienced — space where the imagination seeks to change and appropriate. It overlays physical space making symbolic use of its objects. Thus representational space may be said, though again with certain
exceptions, to tend towards more or less coherent systems of non-verbal symbols and signs. (39)

In “Terra Incognita,” the speaker decodes the space, reading its signs, picking out the “webs” of dew drops on the grass and like a traveller adrift at sea, uses them to navigate the earth (OB6 5).

The relational elements of the navigated space are at once familiar and surprising because Kuusisto does not depict visual truths; he subverts mimetic representations of ocularcentric perception. Marina Buckler observes “the way the dots of moisture reflect the morning light above is true; nothing about it strikes as incorrect. And it is this fact which forces the reader to ask how, exactly, Kuusisto accesses this information, how he manages to provide this authority over visual truth” (“Blindness and Image”). The event described in “Terra Incognita,” however, communicates a particular subjective experience of embodied truth to de-familiarise the literal and habitual. Marit Grøtta observes that perception is dependent not only on the “subjective vision” of the particular observer but on their distinctive “idiosyncrasies” (76). The idiosyncrasies that comprise the whole mean that we are all inherently different. As Kuusisto notes:

The fact is that when I enter a room or a meadow or walk across the deck of a ship, or I'm lost in the middle of a city I don’t know, I am experiencing space in all kinds of ways that the sighted person does not and cannot. I can’t say these are better, but I can say they are different. (Lia Purpura “Attendant Sunrise”)

Kuusisto’s words remind us to consider the conundrum of how a blind person registers, then communicates the difference between night and day. The enclosed garden terrain, for example, is surveyed in the darkness, as if looking through another optic device, a camera obscura. Inside the dark space of the camera box container, the lens or pinhole image is reversed and the landscape magically inverted. The words “thought” and “pictured” indicate the process of making and reinterpreting the orientation of relational objects (OB6 6-11). The ground is lit from below by the starry dew. The viewpoint shifts and the intricate symmetry of the cobweb-objects appear to drift...
upwards “like anemones” and the sea becomes the sky above. Memories and feelings are threaded together between the lines and stanzas through the repetition of the first person viewpoint. The verbs “I walked,” “I made,” “I thought,” “I pictured” depict the dynamic activity of negotiating the shifting, generative, diaphanous transcendent space (OB6 1-11).

Ironically, a photographic camera typically freezes a moment in time, limiting the photographer to depicting existing objects and realities. Kuusisto’s rapidly changing images present multiple interpretive views. They apprehend the recollected past of the narrator who “walked in the yard” as a series of snapshots suggestive of an open-ended process of becoming (OB6 1). Through enjambment these memory fragments accumulate climaxing at the end stopped “Until we knew what to make.”(OB6 10). Suddenly, the cobweb threads unexpectedly convert to “brilliant yarn” and cotton “skeins” (OB6 7). Thoughts connect, extend and transform in a continuous re-interpretation of reality and qualitative properties. In the concluding stanza, for example, the speaker imagines a shirt made from the yarn as a protective covering. The fabric makes the body invisible so that he might “vanish” from view in the new daylight (OB6 13). The poem’s ending blurs the boundary between dreams and reality. The adult poet reflects on the youthful dreams of utopian innocence - one where marvels of workmanship between humankind and nature are harmonious. In the protective confines of the garden, the child finds a temporary sanctuary. They are, as Foucault observes, the space of dreams:

The space of our primary perception, the space of our dreams and that of our passions hold within themselves qualities that seem intrinsic: there is a light, ethereal, transparent space, or again a dark, rough, encumbered space; a space from above, of summits, or on the contrary a space from below of mud; or again a space that can be flowing like sparkling water, or space that is fixed, congealed, like stone or crystal. Yet these analyses, while fundamental for reflection in our time, primarily concern internal space. (“Of Other Spaces” 2-3)
Yet as Foucault notes, because the space of dreams and the interior imagination are separate from the real world, Kuusisto’s poems are a reminder that some attitudes cannot be changed and medical conditions cannot be cured or mastered by sheer will power and positive thinking. The sanctuary of the space of the imagination is recognised by Lemon who notes that “not being able to see forced me into an extended stay in my imagination . . . My imagination balloon; it became wonderfully corpulent. It became a place of safety and pleasure” (168). Kuusisto describes his struggle to accept his blindness as possessing “a craving to appear like his peers” (Fletcher “Steven Kuusisto” 616). His early life with blindness is one of isolation and anxiety mixed with the exhilarating but terrifying experience of negotiating space. Being restricted in sight, Kuusisto is “caught between warring snakes of definition: blind I’m a fatted failure; posing as a sighted person, I’m on a terrible high-wire” (P42).

Against the backdrop of his “loving, eccentric, well-meaning, dotty” parents’ refusal to openly acknowledge his blindness and his own determination to function without support, Kuusisto struggles to assert his independence (41). He comments, “I would conquer space by hurtling through it” (P8). His conception of himself is of an individual recklessly speeding through unknown terrains; he is simultaneously terrified yet elated, driven by a necessity to control space and overcome its parameters. It is indicative of his utter refusal to accept being defined by blindness. He shuns being mediated by the values imposed on him:

There’s a power that comes with admitting how little I can see because the world is more open and admits me far more generously than it did when I was in the closet. But it’s hard in a different way. You are watched everywhere you go, and sometimes I feel buried beneath the graffiti of other people’s superstitions. (P184-5)

He refuses to position himself as a subject encoded by predetermined ways of looking. He resists being “buried,” oppressed by the gaze of sighted observers and subjected to the “graffiti” language of reductive commentators (P185). These concerns resurface in the childhood poem “No Name for
It,” which invokes the Scandinavian culture in which Kuusisto was raised. He exposes the oppressive power of language by stripping away the linguistic roots of words written in his native language. This introduces the topic of the perception of the self from the perspective of an individual with little knowledge of the cruelty of the wider world. It establishes how an individual’s way of seeing themselves is often subject to the gaze and language of others. The poem also articulates the impact of hearing and sound in making invisible absolutes visible.

The opening stanza of “No Name for It” describes climbing up steps in the stairwell of the family apartment. The incident recalls an experience that occurs in relative safety but exposes the speaker to societal attitudes and practices just beyond the liminal threshold of the front door. The event is also detailed in a blog entry where Kuusisto recounts meeting an old woman on the stairwell. He details the impact her language had on his sense of self: “Tsk, tsk [sic] needs no translation, even to a boy. I was a blind child, and there, on that stairwell, in the curving darkness, I received my brand—was branded. . . I absorbed some very unrefined ideas about physical difference and human worth” (“A Letter to Boy Blue”). Words burn like a “brand” into the external body surface leaving their mark on his interior psyche (“A Letter to Boy Blue”). The poem, I contend, asks us to think about language by crippling conventional idioms and colloquial expressions of visual impairment: being ‘blind to truth’ and, therefore, ignorant of the arguments of reason, or having a ‘blind spot,’ an inability to notice something obvious to others (OB1 2). These idioms are representative of what Julia Kristeva terms the “inertia of language-habits” which his poetry strives to overcome (28). Colloquialisms are interlaced with abstract, pejorative utterances like “nonentity” and “a type of ghost” to emphasise how language ties us to “certain linguistic (psychical, social) networks” (Kristeva 28).

The title “No Name for It,” emphasises the prejudicial nature of many dominant cultural codes and linguistic habits. It exposes the paucity of current language use in relation to disability: there is, “no name,” no a priori, pre-existing, self-evident way of delineating the experience of
visual impairment. This incapacity is emphasised by the pronoun “It” (Christopher Kabacinski 53). The reductive word “It” is indicative of the destructive force of the matron’s language and representative of societal attitudes which dissipate his sense of self. This sense of detachment is emphasised through the use of hyphens, bracketed asides and the fracturing use of semicolons. Conversely, the poem’s tight couplet structure replicates the rigid imposition of definitions. The verse’s truncated rhythm accentuates these binaries by running parallel labelling structures. The Swedish is directly linked to the English counterpart:

Start with a hyphenated word, something Swedish -

*Rus-blind*; “blind drunk”; *blinda-flacken*; “blind spot”;

*Blind-pipa*; “nonentity,” “a type of ghost.”

*En blind hona hittar också ett korn*;

“The fool’s arrow sometimes hits the mark.”

(That’s what the Swedish matron said)

When I was a boy climbing stairs)

She pointed with a cane: *Tsk,*

*Barna-blind*; “blind child.”

Her tone mixed piety and reproof - pure Strindberg!

It echoed on the stairs, *barna-blind* -

“Blind from birth.” *En Blind hona hittar . . .*
The blind child’s arrow . . . (OB5 1-13)

Italics and inverted commas indicate the foreign language entries and idiomatic expressions. The alternating typographical pairings of “Barna-blind; ‘blind child,’” for example, are compiled like entries in a personal reference entry in a dictionary of translations (OB5 1). In her comments on language categorising blindness, Julia Miele Rodas asks:

What does this word ‘blind’ really mean? Is it descriptive of an established condition, a measurable physical disability, the lack of sight? Or is it, perhaps, the naming of an ambiguous and ephemeral category, a linguistic gesture, an attempt to restrict and to codify, to define and delineate an arena of sensation that ultimately cannot be disciplined? (116).

Kuusisto’s speaker mocks examples of these “linguistic gestures,” reiterating phrases that are memorized like nursery rhymes as part of his youth (Rodas 116). Kuusisto notes that poetry has a capacity to change linguistic constructs through what he terms a “polysemous opportunity to rename things,” arguing that “if the world is difficult for you, you have the opportunity to be renaming it at every turn” (Niord4360). He reclaims the word ‘blind’ by using the term and describing what it “really” means from his perspective (Rodas 116).

“No Name for It,” represents this process of renaming by undermining its own list-like organisation. Lines are fragmented through the hiatus created by the commas and caesurae, insertions of free indirect discourse, hyphens and ellipses. According to Kabacinski, Kuusisto’s poetry becomes an exploration of the dynamic possibilities of language “insofar as the young Kuusisto eschews the conventions of language, of meaning” (54). The dynamic tensions and textures of the quotidian binaries creates a synaesthetic merging of what is heard and what is seen. The Swedish matron’s voice intrudes the space. Her utterances emit an onomatopoeic sound in the tutting reprimand and disapproving, “Tsk tsk” (OB5 8). The linguistic labels make the speaker’s concealed blindness acutely visible and the revelation exposes the vulnerability of the interior
psyche. Words pierce like arrows, wound the interior psyche and map the body surface like scars:
“But of course I’m carrying nothing except my sense of not-quite-belonging, which I’m fighting like a man swatting hornets,” a foolhardy action given their painful sting (P67). Kuusisto notes the nonsensical nature of attempting to fit in: “I’m doubly blinded by both the pejorative value of sight loss and by the illusion I can ever achieve my own value. The very notion that one might achieve subjective satisfaction of any kind is foolish. Let us richly theorize the fool’s errand” (“Just a Map”). “No Name for It” represents the speaker’s wishful thinking in the typological gap suspended between the two ellipses. The movement in time is conveyed by the altering of the cliché “fool’s arrow” to the concluding “child’s arrow” (OB5 13). The repetition of “arrow” reverberates and like the “tsk” reprimand echoing in the stairwell, the words vibrate against his contour (OB5 8).

These reverberations of words across time counter Bachelard’s hypothesis that “Memories are motionless, and the more securely they are fixed in space, the sounder they are” (Poetics of Space 9). In the enclosed space of the stairwell, words generate a frisson of understanding between one experience in time and the other, heightening recognition of the affective quality of the experience (Poetics of Space 9). The words and “taps” of the cane echo in the stairwell and, as if placed on an elliptical loop, the distant past reverberates within its own echoes. Bachelard observes that “Even a minor event in the life of a child is an event of that child’s world and thus a world event” (Fragments of a Poetics 33). The sound of the Matron’s words have a significant impact in Kuusisto’s formative years:

My minor event, the naming of my blindness . . . there are two ways Bachelard can be right. The first is that the old woman’s contempt becomes a cathected and insupportable incitement . . . The second is this small, nearly infinitesimal occasion turns me to making things . . . In both cases a child’s world grows upward and outward and influences many people over a lifetime (“A Letter to Boy Blue”).
Kuusisto remarks upon the “infinitesimal” event as one that has a fundamental impact “influencing” his consciousness (“A Letter to Boy Blue”). In “No Name for It,” this change is represented in the way the “fool’s arrow” transforms into the “blind child’s arrow” (OB5 13). The “naming of my blindness,” is an exposure of the self, driving “upward and outward” into public expression by writing poetry (“A Letter to Boy Blue”). It drives him to resist being reshaped, altered by cultural and social paradigms of the environments he inhabits, by surrounding himself in a protective layer of his own poesis. He avoids exposure to the words of others by refusing to adopt his own cane which is an “icon” of blindness (Derek Newman-Stille 49). The concluding line “The blind child’s arrow…” in “No Name for It,” is left open ended, questioning where the next arrow will land and what form it will take (OB5 13). The dichotomy is one which Kuusisto struggles to resolve in his formative years. Fear of branding and the stigma of blindness prevents him from being open to others and prolongs the time that outside spaces remain uncharted territories. In the transition to adulthood, Kuusisto expands his consciousness, aiming to “hit the mark” with his own words and creative imaginings by “making things” that hopefully “influences many people over a lifetime” (“A Letter to Boy Blue”).

As a child he learns to contract within the spaces of the mind, removing himself from interactions with others. He states “I am emphatically told not to mix. In some cases this comes directly from the parents, who think I might break during ordinary play” (P12). At university, he must endure the scowls of other students and the resentment of professors who feel he is not physically prepared to complete his coursework. Drawing on his childhood experiences, he uses his poetry to expand into new spaces of knowing: learning what “words can do when placed side by side, I’m starting to build the instrument that will turn my blindness into a manner of seeing” (P66). As Kuusisto indicates, impairment does not prevent people with blindness from registering visual beauty or articulating meaning in wonderfully precise forms of expression and through complex poetic aesthetics. Instead, his words armour and equip him, giving him
alternative, prismatic and inclusive ways of seeing.

**Section Two: Imagined Landscapes and Accessible Worlds**

The poems “Guess,” “Learning Braille at Thirty-Nine” and “Post–Orphic,” all offer an insight into how Kuusisto conceives of the potentiality of reading, hearing and touch as ways of opening up imaginative spaces as sites of literary and linguistic production. Situating the speaker within real spaces, they problematise common depictions of architectural spaces by creating landscapes of abstractions and allegorical associations. They express Kuusisto’s sensory engagement with university rooms, halls and city environments where he lives during his academic studies. However, they displace the concrete and particular with non-specific unadorned settings and abstract nouns. “Guess” and “Post–Orphic” introduce the concept of navigating spatial soundscapes as a form of cognitive mapping through sensory perception. “Learning Braille at Thirty-Nine” evokes touch as a method of acquiring understanding of the external through contact with books and Braille. The cloistered spaces of academia are re-constructed, transitioning between familiar material spaces and others imagined as private gardens and literary utopia. The speaker dwells amongst the sweet sounds of nature ensconced within the protective sleeves of books and retreat within private dreamscapes and newly imagined geographies.

As a young adult, Kuusisto continues to struggle to negotiate physical space. He builds up knowledge through repeated movements, creating mental maps of contained spaces, routinely navigated to ensure familiarity: “I know the campus. I know the sidewalks. Everything else is the great jungle of night, the unfamiliar has vines and teeth. My blind-passing-for-sighted universe is very small, as small as a simple town square” (P77). His “universe” is the physical space of the university town where his father also works. Kuusisto cognitively maps this “small” space using what he calls a “sixth sense”– the sense a person uses to understand the position of their body in
Kuusisto expresses this phenomenological perception of space and movement through touch as “my blindness talking to my feet” (“A Letter to Boy Blue”). In *Eavesdropping*, he comments on the alternating touch and pulse of sound beneath his feet with each point of contact: “Strophe and antistrophe. Step. Rhythm. Pulse beat. I’d crossed a threshold, hearing and walking the uncertain space that opened before me…” (9). Michel Serres identifies a connection between the feet and sound reception when examining types of hearing. According to Serres, hearing is first made by “means of skin and feet, we hear by the means of the muscles, nerves and tendons… we live amid sounds and cries, amid waves” (180). Hearing is considered a distance sense as opposed to touch which is a proximal sense of elements in direct contact; condensing the distance undermines assumptions about visual stimuli being the dominant perception cue. Hannah Macpherson states that attention to the feet rather than hands cripsthe “stereotype of blind touch as primarily associated with the hand” and suggests that “feet are part of embodied processes of immersion and forgetting as well as a source of contemplation, humor, visualization, and dreams” (180). Kuusisto expresses this notion of immersion when commenting:

I think the immediacy of a crippled identity has everything to do with knowing that you are a body—that is, you are not a cognition machine living a separate life from your embodiment, you are the body. (“Crip Street”)  

The perception of space is through a whole body awareness. Kuusisto’s feet and fingers touch surfaces, see through the fabric veils that hide reality from him and hear the vibrating waves of sound, immersing his mind and body as he contemplates, visualises and “dreams” (Macpherson 180). In *Eavesdropping*, Kuusisto says:

My trouble was that I wanted the world to be something like the Aeolian harp. Or at least I thought I did. I wished for an open door, the wind spilling sound from its treasury. And what the hell did I mean by sound? I meant intelligent sound. What did that entail? I
imagined it was sound that carried potential meaning. What did latent meaning mean? Well I guessed it was something you could play with. So I was looking for noises that stirred the imagination. (E123)

In figuring the world as a musical instrument played by the Greek god of the winds, Kuusisto emphasises the movement of sound as it travels in waves from its source to the listening recipient. Sounds are represented as gateways to “potential meaning,” accessed through the “open door” (E123). Within “Guess” and “Post–Orphic,” the space of the imagination is “stirred” by “intelligent sound” but is also protected from unintelligent sound. In these poetic representations of protective, abstract and transcendent spaces, protective borders shield against the external cacophony of sounds, discordant attitudes and societal practices.

The opening lines of “Guess” reference the narrator waking within the space of a bedroom, listening to the radio. The sounds of the radio merge with the raw sounds of nature filtered from the outside; this creates an aesthetic aural landscape that is encapsulated within the poem itself. In the “sensorium of the blind,” sounds permeate the porous boundaries filtering into the interior sensory spaces of consciousness (P7). At first, they are a mixture of voices, instruments, and oral “songs” sung by the early poets, and the words of known and unknown artists:

Because waking, the radio low,
I’ve heard music by unnamed composers,
The puzzle of melody returns to me
To the viola, Kol Nidrei,
Or the oldest songs of the Finns. (OB11 1-5)

The enjambed listing of memories unfolds the “puzzle of melody”; mementos of sounds from his heritage, heard in the “songs of the Finns,” filter from the past and echo like the “taps” on the stairwell in “No Name for It” (OB11 3). The stanza opens with the word “Because” signifying a causal relationship between past experiences and present. David Rothenberg emphasises the
relationship between music and sound as a “bridge between our culture and the unfamiliar” (211). Sound and music cross the boundaries of cultural space. Schafer’s conceptualisation of sound forms a theoretical framework; she defines three main categories: “keynote sounds” (those created by geography and climate); “signals” (sounds which must be listened to: warning bells); “soundmarks” (sounds unique to a community); to which he adds a fourth, “archetypal sounds” (mysterious, inherited, ancient sounds) (9). Kuusisto’s poetry, I propose, resists such simplified divisions. His imagery presents a “puzzle” of connecting vibrations in which experiences of time and space intersect. Kuusisto explains how sound connects across different senses, surfaces and mediums in a more complex formulation:

   All I can do is suggest that I'm an impressionist. There’s freedom in impressionism, and with that freedom comes luck, because then, if your language has a kind of compensatory sweetness, musicality, energy, and rightness, literary consciousness unfolds and something larger than the writer occurs. (Purpura “Attendant Sunrise” 679)

Living in a society in which blindness is perceived as tragic and detrimental to personal achievement, Kuusisto’s response is to immerse himself in nature, music, art and literature. He explores the “intersections between creativity and mindfulness and peace and divinity” (Niord4093). In mindfulness he finds nature; in nature he finds poetry:

   There are walking birds and there are flying birds, and I spend all this time thinking about them, letting them come to me, simply by being in nature, feeling the flow, the electrolysis, the electricity of what is real, which is nature. I’m just trying to let that wash through. Yes, that’s part of listening, but it’s part of an understanding that nature is poetry. (Tyler Dorholt “An Interview”)

Embodied experience is envisioned through multiple levels of rich sensual imagery primarily interpreted and invoked through sound and touch. Donna Seaman observes that soundscapes capture sounds and cultivate a new world of poetic “listeners,” in a visible “visual” landscape (1).
Seaman describes Kuusisto’s poems as “works of spare and musing beauty,” in which “each word is set as carefully on the page as a footstep blindly taken in an unknown place” (205). Schafer asserts that the world is a “macrocosmic musical composition . . . all sounds belong to a continuous field of possibilities lying within the comprehensive dominion of music. Behold the new orchestra: the sonic universe!” (5). Kuusisto’s distinctive sonic universe is constructed as an auditory space, an environment with varying intervals of sound and silence echoing, reverberating and supplementing visual description:

The fields are swept by a music
Half–heard when rising,
No sound, blue intervals,
Then the next phrase
While rain streaks the windows
And the vibrato of recurrent wind
Tells of the waning moon
And Mendelssohn’s fiddle. (OB11 6-13)

The window’s glass marks a transparent architectural border between inside and outside spatial zones. The sounds of nature play against the glass in a synaesthetic-like experience where stimulation of one sensory or cognitive pathway elicits an involuntary stimulation of other auditory, colour and tactile stimuli. Serres comments on the endless possibilities of “hearing” distant space by mingling the object of the senses and the instrument of sensation: “I can put the ear on the other side of the window, projecting it great distances, holding it a great distance from the body” (119). In “Guess,” depth of perspective is ambiguous. The sibilant sounds of wind, rain and “streaks” of nature appear interchangeable with the soft voices and music from the radio (OB11 10). The oxymoronic juxtaposition of the “Half-heard” and “No sound” merges sound with silence in a synthesis of discrete experiences of visual and auditory perception (OB11 7 8).
Kuusisto notes “that one needs to be open all the time to lucky possibilities in the soundscape. These things might be a personal ‘found music’—an approximation of the visual world” (E76). Being open to chance, to the potentiality of “lucky possibilities,” is an alternative way of experiencing space (E76). Like the poem’s title, the speaker enjoys freedom through the experience of inexactitudes and guesswork.

In “Guess” the personified onomatopoeic wind “tells” the melancholy song of the “waning moon”; this solemnity is juxtaposed by the joyous music of Felix Mendelssohn (OB11 12). Jérôme Staub and Eric Sanchez argue that sounds help us understand our environment: “listening to sounds, recording sounds and restoring a sound environment all aim at grasping reality” (193). Kuusisto observes that listening to Mendelssohn confirms “sound is permanent– a continuous wave throughout creation…and now the string theorists confirm it. We are vibrating endlessly in the present, which is also the past and future” (E70). Sounds emerge and serve as markers used to interpret and pinpoint various objects occupying differing spatial zones. Through this process, according to Nick Couldry, “the world becomes intimate, known and possessed” (283). In this context, sound is viewed as a permanent, underpinning universal mode of perception which resonates like the “vibrato of recurrent wind” across time (OB11 11). For Kuusisto, sound is synthesized with seeing and touch in ways that emphasise instability and impermanence. In Eavesdropping, this transience is suggested by the motif of “ice” and alludes to the ephemeral qualities of ice, its contours and structural form:

And birch trees swayed, their skins of ice making a bright, sympathetic sunlit music. I shook the birches one by one and was rewarded with the sound of ice skittering down from the high branches. I loved that confusion of ice with its thousand tiny blades all cutting at the light (E14).
Kuusisto delights in touching objects in nature, making contact with their surface “skins” and ambiguous “confusion” of form (E14). The dynamic flux in nature is missing from societal practices which attempt to fix, label and contain.

In “Guess,” the allusion to rhapsodic, ritualised Solomonic chanting, metaphorically epitomises the habitual use of language that repeats without variation or fresh insight. The pivotal “But” emphasises how reality can be “freed” from the burden of preconception of “other people’s words” erroneously accepted as absolute truths (OB11 19). On this occasion, the glass window offers a protective veil, a “private,” emancipating space where the demarcations between past, present and future are blurred (OB11 14):

It’s a private, chalked-out game
As December collects and snow begins.
All morning I carry other people’s words,
Advanced the clock, talk through habit,
But early, the music lets me stand –
Freed from opinion into guess,
A place I need as some need ends.
I walk between pillars of silk,
Hear the rhapsody of Solomon.
The Hebraic dawn opens again,
A windfall, and I hesitate. (OB11 14-24)

The line “It’s a private, chalked out game” is suggestive of memorised words and mapped spaces (OB11 14). Games can have rules and regulations rather than luck and chance. Kuusisto says, “I lived a kind of charade of being in the world, hoping to be seen as a visual person, but really insufficiently capable of living an adventurous or outgoing life” (Niord4135). He is metaphorically tied, like the blind Solomon, to the small, contained spaces: “In fact, you go nowhere - you stay in
a very small circle” (Niord4158). The enjambed verse illustrates the intellectual and emotional strength needed to break free from the “pillars” of antiquated philosophies, traditional historical, environmental and cultural habits (OB11 21). The word choice “guess” is juxtaposed by the constraints of “opinion” emphasising this liberation from narrow definitions of ocularcentric notions of perception (OB11 19). Old habits of listening are represented as “ends” tied off like empirical proofs (OB11 20). The imagery acknowledges the abstract sense of standing still in the experience of the moment. The poem’s concluding word, “hesitate,” suggests a moment of underlying doubt and uncertainty. Sounds vibrate and bleed into one another; in “Guess” they are “Freed,” expansive and uncontained, floating, dispersed as “windfall” (OB11 24). Poetry liberates them. They multiply within the metaphorical garden of his imagination.

Kuusisto explores representations of the sense of touch to explain how tactile engagement builds understanding of the relative locations and physical organisations of space. Morton Heller argues that when blind people read Braille using touch “they get a sense of space” (77). However, Kuusisto is also concerned to illustrate how a non-physical touching of minds is achieved through the relational positioning of words. His poems widen our thinking about the boundaries of haptic perception and how we access the minds of others. In the poem “Learning Braille at Thirty-Nine,” the words of other writers are represented as metaphorical “seeds” of knowledge (OB8 3). Given his love of literature, Kuusisto at 39 learnt Braille comparatively late in life. The poem conveys how the new skill of reading Braille gave him greater access to other people’s thoughts. It illustrates how books and language connect individuals in both real and imagined ways. It shows how words made public in poetry form a porous surface of communication that bridges the gulfs of social disconnection. As Buckler observes:

It seems to be precisely this disconnect that Kuusisto aims to draw attention to in his poems about blindness. His work forces the reader to confront the idea that the task of describing the world we inhabit, with its rich tapestries of shadow, does not–must not–belong solely to
the sighted. That the way we think about the disabled body in our society—by thinking of what it cannot do, as if the person operating with a disability is operating at a deficit, encumbered with a projected loss—marginalizes the experiences of the disabled person, categorizes those experiences as less, and sets them aside. By imposing this thinking onto the disabled body and the person living within it, we provide one more barrier for the disabled person to internalize, and to struggle against. (“Blindness and Image”)

Kuusisto rewrites his own narrative, utilising the interior spaces of the imagination and literature to resist externally imposed barriers. Whereas formerly Kuusisto represented his experience as drifting like “spindrift of ocean liners, streetcars, and stairwells,” blown about by the wind and unseen forces of fate, now his metaphorical seeds take root in the imagination (P11). He desperately attempts to stay afloat, to belong, to “stay on the same ocean with the others,” but it is through books that he connects to the outside world, to other minds and feels free to dream (P43).

In “Learning Braille at Thirty-Nine,” seeds are planted in the body of the poem as allusions, references and quotations which germinate new language and ideas. They are literally and metaphorically grafted onto the stems of other people’s cited sentences. For Norma Cole, the concept of “Word-seeds” refers to “Sphota,” the “eternal appropriateness” of words which, according to Bhartrihari, communicate the apprehension of the original seeds of “ideas that pre-exist words and objects” (258). Since individuals have ideas “before one has the words to say them,” the role of the poet is to find the words to best describe these ideas (Cole 258). In “Learning Braille at Thirty-Nine,” these seeds mature and bear “fruit” when planted in the speaker’s writing and imagination (OB8 2). In biblical terms, the seed is the “Divine Word” and of Divine Origin, signifying Creation (Stephanie Theodorou “Bhartrihari c.450—510 C.E.”). In a Bhartriharian view of the cosmos, the universe is one of “constant and cyclical creation and dissolution” (Theodorou). At the dissolution of each creative cycle, “a seed or trace (samskāra) is
left behind out of which the next cycle arises” (Theodorou). Seeds, therefore, are representations of renewal and rebirth.

In “Learning Braille at Thirty-Nine,” the seeds are also representations of the raised bumps of Braille. Kuppers describes the tactile qualities of embossed pages of Braille: “This is a lovely shaped thing, with ridges, dashes, dots, commas . . . with the embossed figures deep in the grain” (“Performing Determinism” 101). The speaker touches the grain and reads the seeds set out in their special formations on the spaces of the paper. Pages from the “dry” classics are harvested (OB8 1). Ancient texts are revitalised; antiquities give up their hidden treasure. The secrets of the universe contained within literature are unveiled, their inner workings revealed like an exposure of first thoughts making the origins of things known. Teare notes that in the moment, the “mind and body act in concert to construct our interdependent sensations of consciousness and selfhood” (148). As part of the speaker’s surreal landscape, “Pascal,” like Salvador Dahli “dreams of a wristwatch.”

Time melts, past and future spaces overlap:

The dry universe

Gives up its fruit,

Black seeds are raining,

Pascal dreams of a wristwatch,

And heaven help me

The metempsychosis of book

Is upon me. (OB8 1-7)

The finger passes over the seeds to read the words of the text. Touch is the dominant sensory means of promoting and understanding ideas. Words cascade in rain-like replenishment, a life-giving force that offers sustenance, understanding and insight. Kuppers emphasises the hardened shells of the poem’s “black seeds”:
This sparse poem raises up letters and short words, staccato, widely spaced in my mouth—to be read, a dried universe, with the labor of harvest, like many new immigrants bowing backs and splitting fingers—although the sparseness of fruit and black seeds seems too hard-shelled, contained, to allow me to veer widely. But the black seeds quill up, drawing in liquid, breath, and as the poem descends, exciting words spill forth, like ‘metempsychosis’ the transmigration of spirit and the rhythm quickens. (‘Performing Determinism’ 101)

In “Learning Braille at Thirty-Nine,” the speaker dwells amongst the ghosts of the literary past and through a process of “metempsychosis” (meaning a transmigration of souls into a new body) constructs a new creative voice: “The metempsychosis of book/ Is upon me” (OB8 6-7). Kuusisto synthesises experience, imagination, and testimony through this process of metempsychosis, absorbing the words and imaginings of other writers. Kuusisto describes how he often perceives space through the eyes, voices and fictional creations of other writers: “All of it is glorious, and like my boyhood discovery of Caruso in the attic, Bly’s voice, among others—Breton, Nerval, Lorca—follows me in the dark” (P65). The synthesising of words, conversations and ideas becomes “a lifelong habit,” emulating Socratic discourse in “imaginary conversations with authority figures, usually when I’m touching something, when I’m on the verge of an understanding” (P74). Voices from the present and echoes from the departed, overheard passing conversations, recorded books, traditional songs and contemporary radio music serve as a myriad of unseen sources which conjure imaginary spaces and contribute to his representation of alternative forms of embodiment and ways of knowing.

The dream-like invocations of souls and spirits in Kuusisto’s poetry offer a counterpoint to his representation of the ordinary everyday aspects of dwelling in physical spaces. They form a synoptic vision that renders the external spaces, the physical landscape, as re-imagined inner landscapes of the mind. These inner landscapes are invoked by the sounds and particular
sensations aroused through memories and sensations and transformed by emotional associations. The emotional component of pain and/or delight invokes an understanding that is beyond the physical experience itself. These merging moments of sound, colour, and memory are fragile and fleeting. Books, in their profusion of words and minutiae, give Kuusisto a language to communicate understanding of the ambiguous world. Each raised “seed” when touched, transforms into a means of “renaming of the world,” and in re-naming gives language an inscribed meaning (Paulo Freire xix). In these moments, touch becomes the dominant interpretative source of new knowledge.

The poem “Post–Orphic,” describes how the speaker transformed by “the gift of reading,” dwells in the protective spaces of books, retreating inwardly into the rich landscape of the imagination (Buckler “Blindness and Image”). It explores the “writerly compulsion,” Buckler notes, of being motivated by reading, which Kuusisto elucidates as a sort of “human communion,” an almost tangible, tactile engagement with spirit others (“Blindness”). In “Post–Orphic,” the space of the imagination exists as a utopian ideal, one which refreshes and replenishes, signified in the connotations of “green” as the colour of renewal (OB28 2). The concept of reading space through the distillation of other writers’ words in “Learning Braille at Thirty-Nine” is communicated this time in the allusion to Andrew Marvell’s metaphysical conceit of the mind in “The Garden”: “Annihilating all that’s made/To a green thought in a green shade” (Complete Poems 100 47-48). Like Marvell’s “green thought,” the “green space of the marrow” in “Post–Orphic,” is the fertile ground of the imagination (OB28 2). The space is expansive and felt in the bones of the body. Marvell’s “annihilating all” equates to Kuusisto’s apprehension of thought when “your world becomes larger” (Niord4065). Unlike Eden, Kuusisto’s green space permits access to knowledge; meaning is accessed from within nature, from within the seeds of planted fruits:

Tonight I felt it in my ribs:
A flood of green in the marrow,

I decided to live right here
And sing sometimes.

I pulled a book from its shelf,
Held the minutiae of the world

Open like a killdeer’s wings.
I’ve lived without names

For plants and trees.
What happens now?

What happens? (OB28 1-11)
The opening recounts the epiphany of knowing through sensory sound and touch, one which impresses upon the mind and floods the “marrow,” entering the very threads of his being, represented in the life giving “ribs” (OB28 2). Like Orpheus, the figure alluded to in the title, the speaker elects to stay and sing. Orpheus is the mythical figure whose singing charmed even the trees and rocks and moved them to dance. Like Orpheus, who delights in seeing the world revealed by the sun, the speaker leaves the land of darkness and infertility (OB28 6). The allusion equates the speaker’s awakening to a new knowledge of the “minutiae of the world” (OB28 6). He basks in the illumination that books bring and dwells amongst their thoughts. Kuusisto says that what makes him an artist is an “affection for the minutiae of experience, and for the improbable nature of experience” (Niord4037). The miniature nature of the “bright moment” is paradoxically
expansive (*OB28* 8). The pages of the book fall open, fan-like, feeding his desire and letting his imagination take flight on the “wings” of birds (*OB28* 7).

Being newly attuned to pure sensation, the narrator chooses to exist in the “here” of the liminal space of the moment (*OB28* 3). Roz McKechnie notes that being in a transitory position of liminality, “people can move between different communities and experience different frameworks so that new ideas and knowledge emerge” (11). Kuusisto argues that being an artist is imbued with a “heightened quality of apprehension and awareness about time, about the moment, about imaginative possibilities” (*Niord4037*). Before his epiphany, the speaker lives “without names,” the linguistic codes of language exist in a state of innocence (*OB28* 8). The open ended rhetorical questioning, “What happens now? /What happens?” invokes the tension of knowing yet not knowing about future spaces, about our ability to see the beauty in all things and about the capacity of our language to describe them anew (*OB28* 10-11). Kuusisto comments that poetry and art is about “hope. It’s to say life is not static - it’s moving. It's moving all the time” (*Niord4037*). According to Newman-Stille, art posits “a new way of ‘looking’ at the world, a new perspective” (44). Like Plato’s shadows, we too often fail to see the beauty of the whole and lack the language to “sing” its song.

Accessing the imaginative landscapes of other writers does not mean that Kuusisto always finds answers to the problems his poems ask us to consider. Often, answers like objects, remain disappointingly out of reach. He says, “And of course I don’t have any words for my quandary. I recite other people’s words. Lines from the poets…” (*P78*). Kuusisto describes how: “I’m often looking for layerings of imagery that work with a variegated or heaped anger” (Savarese 201). This stratification of imagery, ideas and perceptions gives his work an enigmatic tension, an often cryptic quality as meaning is generated through the gaps between his fragmented poetic couplets. His overlaying of direct and indirect citations reference the work of other writers and thinkers. He assimilates their utterances and reconstructs them, layering them in the sediments of his enjambed
lines. Teare similarly comments that his own embodiment “lead[s] to a poetics deeply indebted to ‘non-normative’ somatic, physiological and cognitive processes as the basis for poetic forms, forms frequently engaged with classic texts from Western and Eastern traditions of wisdom literature” (185). Teare adds, “All along my body has been its own book of wisdom, articulating far more about the terms of living than my mind can always be conscious of” (185).

Kuusisto invites us to think about how poetry is a medium for re-appropriating ideas and language about space. Through moving from the concrete to abstract interpretations of space, he is able to present his own perspective on environments and not be constricted by the need for an empirical analysis of surroundings. Instead, Kuusisto draws upon the “power of oral tradition poetry”; he describes the poet as a narrator who can “create visual tapestries in the mind of others” (Niord4119). He attributes the power of his own poems to an “understanding of how surrealist imagery can produce complex emotional states” (Niord4119). Surrealist imagery can fracture and distort the certainties we hold. For Kuusisto, contesting perception-habits through impressions and guesswork leads to discovery of the possibilities of knowledge through the workings of the imagination, presenting a view of the world where every component of space and its mechanics is open to doubt. In freeing himself from the set frameworks of perception and embodiment, he creates a transgressive dynamism that breaks through inertia and external boundaries that oppress and control meaning.

Kuusisto reminds us that reading books and imaging spaces does not cure blindness. Although learning Braille, listening to recorded books and being read to by others are positive experiences, they cannot themselves draw him out of his personal depression nor significantly alter his resistance to openly declaring his blindness at this stage of his life (Fletcher “Stephen Kuusisto”). As he later declares, “I need people to read me” (P126). To read and understand blind embodiment, we need to read the rhythms and influences that shape our tactile and acoustic environment and entrain the body. Through soundscapes and literature, he engages the
relationships within the self and between the self and the world and articulates these relationships in spatial terms. Yeung locates the “aesthetic and ethical force of poetry” in the “affective realm” of the body but Kuusisto situates them in the imagination (212). Only when he becomes attuned to living with a guide dog can Kuusisto begin to write about transcending the boundaries of his imagination, testing his ability to adapt to shifting acoustic and literary environments of the external world.

Section Three: Transgressing Terra Incognita

In Kuusisto’s later poems, the interior autobiographical perspective shifts and becomes more panoramic as he moves away from the enclosed interiors of the home and the cloistered familiar spaces of the university campus to explore travel and cityscapes. “Guiding Eyes” explores the physical movement of the speaker through the urban centre of New York City; “Letters to Borges from London” extends this transition to the external spaces of the continental cityscapes; and “The Books to Come” creates a prophetic vision of the public spaces of poetry in books of the future. These highly sensory and impressionistic poems capture the urban sounds and conversations of strangers encountered in the cityscapes of Kuusisto’s travels. The terrains evolve as re-imagined spaces of meditation and reflection, eroding the idea of set relational positioning and unsettling established frames of space. They blur the boundary between experience and contemplative thought, between autobiographical and semi-autobiographical memories and re-imaginings. They focus on the affirmative potential of the space between words and ideas to create new relations, new communities and new literacies. Negotiation of external spaces is represented as traveling in the companionship of a working guide dog and through the imaginary companionship of the literary figure JL Borges.
In “Guiding Eyes,” “Letters to Borges from London” and “The Books to Come,” the setting moves beyond the boundaries of the walled rooms of domestic locales, the corridors and buildings of successive university campus placements and the memorised urban spaces of the cities. The speakers of these poems now enter previously uncharted spaces. Kuusisto expresses this pivotal personal transformation: “There came a moment when I realised I’m absolutely unable to satisfy my thirst for knowledge and my curiosity about the planet with my sad, closeted blind identity . . . There came a moment when I realised I would not be able to live in the world unless I knew how to walk in the world” (Niord4162). Combating these personal demons and tempering the terror of the terra incognita where “every arrival is a miracle,” is a process, I argue, that results in an incessant drive to ‘read’ space and to ascribe meaning to his subjective way of being in the world in both Kuusisto’s autobiographical writing and his poetry (P23). Kuusisto demonstrates an ongoing preoccupation with literary voices and the power of language to effect change. He explores a form of literary and linguistic exposure: writing and publishing poems involves bringing subjective experiences into public and collective memory. He represents the process of breaking free from literary constraints and traditional forms of representation through the crossing of boundaries into new terrains. Rather than metaphorically hiding in the retreats of literature and books, these are voices that venture forth in the company of others.

For Kuusisto, embodied experience is a “series of veils” that he learns to unwrap to reclaim his sense of self. The process of manoeuvring through New York’s cityscape depicted in “Guiding Eyes,” is indicative of the change in how Kuusisto approaches his relationship with space but also his shifting interior landscape. After decades of being “addicted to appearing independent,” Kuusisto relents and seeks the assistance of a guide dog (P124). With the help of his “genius” dog Corky, Kuusisto is “returned to life, everything is compelling” (P175). “Guiding Eyes” provides a snapshot of how the experience of unmapped architectural and urban spaces change when accessed with a non-human companion. The short, four line opening stanza
introduces Corky as a working dog “Who, in fact, is more than a dog - /She watches for me” (OB20 3-4). The notion of being “more than” is extended in the next stanza when the nature of the relationship is made more explicit. The image of the unified “twin” minds suggests an intimate bonding (OB20 5). The idea of beings working in harmony is expanded further in the metaphorical transformation of the partnership into a reshaped contour of a half man/half animal form. Whilst the mythical centaur of Ovid’s Metamorphoses is alluded to here, Kuusisto’s figure is of an indeterminate shape:

Our twin minds go walking,
And I suspect as we enter the subway
On Lexington
That we’re a kind of centaur -
Or maybe two owls
Riding the shoulders of Minerva.
The traffic squalls and plunges
At Columbus Circle,
Seethes down Broadway,
And we step out
Into the blackness (OB20 5-15)

The speaker’s re-imagined form is ambiguous: it shifts from a “kind of” centaur into “maybe” the figure of Minerva, the goddess of wisdom, carrying her twin nocturnal owls (OB20 8). The deliberately vague terms create a sense of ambiguity; the caveats make us speculate on what type of transformation is suggested. The representation of animal and human connectivity, however, is not understood as a type of “animism,” a merging which endows “natural beings with human dispositions and social attributes” (Phillipe Descola 87-8). Neither is it a theomorphic construct where the speaker metamorphoses into animal spirit form. Joanna Latimer’s term of “being
alongside” infers that it is possible to preserve division and yet account for close proximal relationships between humans and animals. Latimer’s alongsidedness seeks to preserve a “sense of propinquity,” a state of being near to something, whilst emphasising continued separation (79). The term “being alongside” is developed firstly as a critique of Haraway’s emphasis on the notion of “being-with” that involves connectivity as “process and co-construction of human–non-human animal worlds” (“Being Alongside”8). Haraway’s adoption of the term “being-with” has its origins in Heidegger’s “Being-with” (Mitsein) which emphasises the connectedness of Dasein, of existence with others to the benefit of the whole (12). According to Latimer, Haraway’s “being with” is a “dyadic and totalizing” binary relationship where animal and human parallel each other’s movements rather than a uniting of independent parts (80). Latimer sets out to “re-imagine sociality” in terms of its partial connection in order to present a different view of societal interdependencies and address the asymmetry of relations between human and non-human (80).

In “Guiding Eyes,” the emergent combination is a re-imagined proximal relationship evoking Latimer’s thinking, signifying “partial connection” and mutual autonomous regard suggested by the “we” and continued use of “I” and “She” pronouns (80). This thematic concern with connectivity makes us consider how a blind person reads space, how they see themselves negotiating relational objects and how others might view them. When the speaker is figured as a centaur, a mythical monster, the effect is altogether different from when others label Kuusisto a “Martian” (P22). Micahel Huemer states, “all one is ever immediately aware of is one’s perceptual experiences, or representations of external objects, not the objects themselves” (xix). Significantly, Huemer concludes, “our processes of perception are like a ‘veil’ standing between us and the real world, preventing us from ever really perceiving (objective) reality” (xix). Communicating the experience of blindness requires removing the veil and exposing the interior self. Kuusisto expresses awareness of an inherent vulnerability in opening up to the scrutiny of
others: “Of course being “out” with a disability doesn’t save you . . . Being “out” means you’ve traded the shtick of passing, of invisibility, for adventitious and hourly discourses with opposition” (“Of Poetry, Blogging and Disability”).

The narrator in “Guiding Eyes,” employs the language of speculation: “I suspect,” and “I suppose” (OB20 6-19). The word choice suggests uncertainty, doubt disrupting the linguistic certainties of naming through nouns and labels. Yet, Kuusisto also reveals the agency of the poet’s “hidden tongue” and “rude teeth”:

The poetry cripples wilfully forget the glass room of disability performance, preferring performance that makes the toes curl inside the shoes and the hidden tongue goes exploring the rude teeth. I want that. I don’t want the casual “ooh” and “ah” of the mundane, academic poetry reading. (“Disability at the Window”)

With wilful disruption there is renewal. Kuusisto suggests that literary stereotypes need to be contested and new spaces found for poetry. He comments on re-imagining literary cliché:

I’d like to imagine Tiny Tim as a man who retains a mindfulness about disfigurement, understanding it as a terrible irrelevance, nay, even a drain on human intelligence . . .

Meantime I’m thinking of the arts and of their glorious infidelity to old ideas. (“Disability at the Window”)

This subversive “glorious infidelity” reclaims the narrative, making associative leaps that juxtapose reality and crip conventional representation. For Kuusisto, poetry is a device to refashion inert constructs:

I tend to see poetry as a vehicle for philosophical speculation rather than a tabula rasa on which we scrawl our grocery lists. I like poetry that demands something from the reader and this shouldn’t be confused with style. Poetry that reads clearly can be as inciting to good ideas as a more abstract mode of verse. (“Second Thoughts, Disability Style”)
If poetry is a “vehicle for philosophical speculation” then its purpose must be to explore different realities and to reveal what is invisible by finding the right words (“Second Thoughts, Disability Style”). “Guiding Eyes” replaces empirical perception and traditional examinations of existence with an epistemology which emphasises a multi-sensory path to knowledge and perception. In “Guiding Eyes,” after travelling on the busy New York metro, the speaker emerges on 5th Avenue:

Increasing my devotion full much
To the postulate of arrival –
To how I love this inexhaustible dog
Who leads me
Past jackhammers
And the police barriers
Of New York. (OB20 30-36)

Beauty is found in the soundscapes of the city which resonate through his body and his mind; vibrations from machinery send ripples across the surface of the body. The Arcadian songbirds are replaced by the road diggers. Kuusisto delights in this “neural, icy soundscape of a large city . . . a system . . . of waking up to the quick transformations in a soundscape, especially the ugly ones” (E75). These “ugly ones” are the modern sounds of noise pollution rather than the organic sounds of nature. Schafer notes that noise pollution results in a “universal deafness” because we are “forgetting how to listen” (3). These urban soundscapes help Kuusisto to navigate space:

Not only am I listening for potentially lethal traffic sounds, I’m also listening to memorize below the level of my consciousness, the sound of architectures and machines that I can count on when I am retracing my steps, so that I can find my way back through a very complex architectural maze or place. (Purpura “Attendant Sunrise”)

He negotiates spaces using sounds, smells, touch and vibrations. Siegfried Saerberg describes how “as a blind person, I obtain orientation and generate movement by creating a multimodal space of
related sensory perception in a sensed unity of the world within my felt, tactile, acoustic, and 
olfactory reach” (370). However, the depth and relationship between objects is then problematic:
“As I move from “here” to “there,” its boundary is shifting in space and time; the world within my 
potential reach constantly changes into the world within my actual reach” (Saerberg 369). In 
“Guiding Eyes,” Kuusisto’s leitmotifs of dissolving depths of distance are figured as expansions 
and extensions through an overlapping repetition of vocabulary. The process emulates thinking 
and does not advance the argument in so far that it revisits language as a revisioning act:

I suppose we’re scarcely whole
If I think on it -
//
Did I think on it?

A blessing opens by degrees
And I must walk
Both boldly and ghostly
Down Fifth Avenue,
Increasing my devotion full much (OB20 19-20 25-30)

The rhetorical question, “Did I think on it?” suspended as a line by itself, invokes Cartesian 
speculation on thinking and knowing and the differences between animals and humankind. The 
spatial gap between the “If” and “Did” disconnects the “I think” from the implicit “therefore I am” 
(René Descartes Discourse on the Method 32). The poem also crips the notion that embodied 
wholeness is dependent on adding to or replacing something missing, like a much needed 
appendage. In fact, Kuusisto observes: “HOW STRANGE IT is, sometimes, to be Corky’s human 
appendage. Often people stop our forward progress and speak only to her, as if I do not exist” 
(P179). The word choice “blessing” and “devotion” and “animal faith” emphasise a spiritual
bonding suggesting an almost mystical belief in fate and shared destiny. Kuusisto comments on this interconnection of the body, spirit and mind when referencing the poet, Donald Hall:

[Hall] talks about “reasons for moving” and that you keep moving all the time, whether you’re walking or writing, that the flow of your imagination is what matters.” Well, that’s the flow of the spirit. You can have a very dark moment one moment, but then you can turn the corner and be in a rather remarkable and beautiful situation. To stay open to that changeable possibility both of life itself with its improbable glories, and also the flow of the mind, and the way the subconscious and the natural world will move and change - is a kind of spiritualism. (Niord4037)

Venturing forth into the cityscapes, Kuusisto’s courage is continually tested. As an act of faith, he steps out into the flux of movement to become part of the “flow” of the external spaces (Niord4037). In Planet of the Blind, Kuusisto announces: ‘I want to travel everywhere. The dog will be my constant companion. She’ll be my eyes’ (171). In “Guiding Eyes,” the speaker is represented as being undaunted by the endless variety of the architecture, unpredictable movements of city dwellers and the fast moving cacophony of voices and vehicles which have to be navigated without aid of physical maps. It problematises experience as a series of anticipatory acts of speculation by showing the unpredictable nature of encounters. It explores different realities to reveal the merging of reality and myth, uncertainty and doubt blurring the boundaries between real and unreal.

Kuusisto’s second poetry collection, Letters to Borges, develops the idea of being with others as part of an imagined literary community and conceives of this as a shared space. The companionship this time is with the re-imagined literary figure of Borges. The poems are often written as communications in the transactional form of letters, sometimes as dialogic representations of face to face conversations and others as interjected thoughts randomly addressed to Borges. In the opening stanza of “Letters to Borges from London,” reference to Borges is
implicit. It is made in the allusion to the literary conceit of Borges’s labyrinthine libraries of the imagination. The poem’s narrator initiates a metaphorical construction of a new thought by juxtaposing the past with the present. The layering of time is represented spatially through the segmented typographical sequencing of the two stanzas. The first stanza recalls the memory of making a beehive from old letters:

When I was a boy I made a beehive
From old letters- dark scraps from a trunk,
Lost loves, assurance from travelers.
It was intricate work.
The blind kid and the worker bee lost whole days.
I made a library for inchworms. (LTB16 1-6)

The motif of the beehive as a metaphor for a literary spatial universe invokes Borges’s labyrinthine library of hexagonal patterning: “The Universe is composed of an infinite number of hexagonal spaces that the unnamed narrator was born” (The Library of Babel 19). In this infinite universe, the same ideas and plots are written repeatedly with every possible permutation perpetually reappearing: “The universe (which others call the Library) is composed of an indefinite and perhaps infinite number of hexagonal galleries” (The Library of Babel 1). Regarding books as a medium for predicting what will happen in the future, Kuusisto, like Borges, is using spatial thinking to consider the relationship between autobiography and literary production. The interplay between autobiography, words, perspectives, cultural codes and poetics is problematised as elaborate rituals of memory and future thinking. Kuusisto comments that Borges “imagined Paradise would be a library and there is something of the vatic about reading. One way to think about this is that the very act of reading—the first effect of literacy—is that the reader is granted the opportunity to question the language itself” (Appendix 2 277). The language that constructs
blindness “is so diffuse, and has so widely infiltrated our figures of speech, that it, too, is inescapable. Authenticity retreats” (Rodas 129).

In “Letters to Borges from London,” the unlocking of information through books and language is a process of industry and nurture. The beehive is tended by workers; its craftsmanship an “intricate” spatial construction (LTB16 4). It is also a product of individual agency, emphasised in the repetition of “I made” and suggested by the split between the “blind kid” and “worker bee” (LTB16 1). The analogy of the two entities working alongside each other suggests the pollinating ideas from one script to another. In this manner of working, “whole days” are “lost” (LTB16 5). The idea of lost time invokes Borges’s literary ruminations on time and the infinite characterised by his famous observation:

A man sets himself the task of portraying the world. Through the years he peoples a space with images of provinces, kingdoms, mountains, bays, ships, islands, fishes, rooms, instruments, stars, horses, and people. Shortly before his death, he discovers that the patient labyrinth of lines traces the image of his face” (Dreamtigers 93).

This image of lines tracing the “image of his face” links to the idea of bodily contours as connected to physical landscapes and interior mindscapes (93). If the hypothetical man finds the image of his own face staring back then the implication is that he has discovered what was there all along. It could be interpreted that time has been wasted. In “Letters to Borges from London,” however, the bee is synonymous with industry and productivity. In childhood, the hive is the miniature space of occupation of “inchworms” whose Latin name derives from geometra and from the Greek geometer (γεωμέτρης) meaning earth-measurer, in reference to their looping gait. The image conjures the painful, inching process of navigating life’s mysteries in the microcosmic existence of the attic space.

For Kuusisto, the Borgesian labyrinthine journey of self-discovery is one which also alludes to the second part of St. Paul’s speech in 1.Corinthians 13:12 “For now we see through a
glass, darkly; but then face to face: now I know in part; but then shall I know even as also I am known” (P1). The allusion emphasises humankind’s obscure or imperfect vision of reality, our propensity to look through something rather than apprehend directly. The expression means we do not now see clearly but at the end of time, will do so in the future. The implication is that despite staring “at the world,” clarity does not come from face to face observation or immediate points of contact but from revelations in the time to come (P1). Truth manifests in future spaces. Kuusisto’s poems, I argue, explore how those future spaces might be represented in ways that make us reconsider how we see embodiment.

The second verse of “Letters to Borges from London,” shifts to present day adulthood, the speaker is “Now” a designer reconfiguring material shapes through his imagination (LTB16 7). He declares himself a “natural philosopher,” all matter and its infinite potentiality is the subject of his study:

Now I’m a natural philosopher but with the same restless hands.

Some days I put cities together-

Santiago and Carthage;

Toronto and Damascus.

If strangers watch closely, Borges,

They’ll see my fingers working at nothing. (LTB16 7-12)

The image is of a master creator of spaces invisible to others: his hands work at “nothing,” his fingers touching imaginary spaces as he manipulates memories into imagined possibilities (LTB16 12). These spaces of activity are “neither here nor there,” they exist in the lumen (McKechnie 11). Real and imagined spaces are reconstructed as metaphorical designs of universal spaces:

In Hyde Park near the Albert Memorial and alone on a bench

I reconstructed the boroughs of New York -

Brooklyn was at the centre, Kyoto in place of Queens.
This was a city of bells and gardens, a town for immigrants. (LTB16 13-16)

In the space of the imagination, he challenges the marginalisation of individuals who are made to feel like “immigrants” (LBT16 16). The displaced and dispossessed find a place to dwell in the new cities of his creation. Kuusisto summarises this agency: “I think the poem offers us an ongoing hopeful range of possibilities” (Niord4032).

In the essay “Keeping the Knives Sharp,” Ferris comments: “I was asked if artists today have responsibilities to those who come after us . . . I hope: to keep the knives sharp” (93). Kuusisto has a similar idea of labouring in order to sever bad linguistic habits from good:

So the knives are out on the inside with a lot of intellectual and artistic struggle, but as we grow older, we find names for things that oppress us, and we give them new names, and we build a different kind of dramatic relationship with those things….to find new narratives for your suffering. (Niord4202)

These “new names” and new worlds are given spatial form in “The Books to Come” (Niord4202). The speaker emerges as a prophetic figure with poetry represented as a way of entering a shared space in which past, present and future coexist. The line “The poet has died, but he will become his admirers” illustrates the conceit, citing “he became his admirers” in Auden’s eulogy “In Memory of W.B. Yates” (17). He adds that “this is an incredibly hopeful thing - the poetry goes on in strangers. It goes on in the extended culture of the living. This is a very hopeful thing all the time” (Niord4052). The hope is expressed in the repetitious patterning of the title words “the books to come,” a phrase reiterated a further five times over the course of the poem. The chanting refrain emphasises not just the circularity of meaning but the momentum of changes in meaning. It echoes Friedrich Nietzsche’s theory of “The Eternal Recurrence” from The Will to Power (1901) which states that “Everything becomes and recurs eternally” (1058). Each “book to come” is contained, in part, within the text that is being written. Like Borges’s labyrinths and Kuusisto’s beehives, they are part of an interconnected structure. The phrase, “books to come,” appears
unexpectedly, the fluid placement suggests the many different textual and linguistic possibilities at play here:

Better than the view of Mississippi clouds

Floating like mares’ tails

But not better than our own sky,

The books to come. (*LTB*10 1-4)

The inward-looking first person form of address is replaced by the collective “we,” “us,” and “our,” creating an outward looking focus on the life to come, “the life you will know” (*LTB*10 3). McKechnie argues that the “liminal challenges us to negotiate meaning, and both the form and the trajectory of our lives can be reshaped at will, whether our own or another’s” (11). In “The Books to Come,” a mood of contemplative optimism comes from understanding that there is a future, the trajectory of change signified by the future tense. This future is enriched by memories rather than reductively contained by habit. It emphasises the potential for innovation, rather than allowing language to stagnate, label and stigmatise.

The notion of humankind’s primitive, instinctual search for fundamental truths is established in the reference to being “alive” and open to new stimuli (*LTB*10 7). The parallel structure of the alliterative “wherever” and repetitive “We” represents a corporeal and mental fusion of instinctual human-animal systems of “hands,” “nerves,” “muscles” fusing with “minds”; it emphasises the vitality of being receptive, open to new thoughts, sensations, and experiences (*LTB*10 10). Kuusisto conveys how we improve our navigation of the world by the very act of being open to exploring new spaces:

This morning, wherever

We open our hands,

We are alive like animals:

Truthful, making our way,
Nerves and muscles strict,
Green maps in our minds. \((LTB10\ 5-10)\)

The image of hands opening here suggests not only a search for reassurance in the physical world, as in “making our way” by feeling textures, but also a metaphorical opening up of the spaces which drive the creative process \((LTB10\ 8)\). Brian O'Shaughnessy states that touch is the “one sense that necessarily is concerned with the spatial properties of material objects” \((673)\). In “The Books to Come,” however, Kuusisto explores how touch is concerned with the spatial properties of metaphorical constructs as well as material objects. The stanza concludes with the image of “maps” and connects this to interior landscapes, celebrating them as a literary tool to navigate the expanded spaces of “our minds” \((LTB10\ 10)\). The alliterative symmetry of “maps” and “minds” appears to shorten the space between them into a compressed thought \((LTB10\ 10)\). Kuusisto extends the metaphor this time to incorporate the notion of the mind as a future space for exploration. Contained in the universal library of the mind, all knowledge from books is stored but not necessarily mapped and understood. According to Alfred Schütz, every acquisition of knowledge is based on “two primordial principles: experiential subjectivity and sociality” \((Saerberg\ 367)\). In other words, all socially based and culturally mediated knowledge is subjective and acquired through immediate and personal experience. Schütz emphasises the temporal nature of this acquisition of knowledge dividing between “the world within my actual reach” and “the world within my potential reach” \((306-8\ and\ 326-9)\). In doing so, he emphasises the proximal relationship and suggests the subjectivity of experience as a “temporal horizon,” one that distinguishes between the knowing \textit{now} and the attainable \textit{future} spaces of what will be known \((Saerberg\ 367)\).

In “The Books to Come,” space and time overlap. In the gaps between lines there is the space of authorial “silence,” the “narrative rupture” of what is left “unsaid”; within this space of “absence” a connection with a priori texts forms and the new text comes into being (Pierre
Macherey 85). For example, the acquired meaning of each line consolidates into a central idea revealing a “latent knowledge” underneath the textual surface (Macherey 92). This is emphasised visually in the poem by the structural patterning of “A” and cumulative impact of the repetitious “And” (LTB10 12). The sense of being propelled forward is achieved by a lack of punctuation and the enjambment which “Tricks” the eye in a compelling forward momentum:

   Ahead of us the day waves long branches
   And the grass offers resolution
   And the solarium of each minute
   Draws us into chances,
   And every embrace of time

   Tricks us into myth. (LTB10 11-16)

Reading books is presented as a source of growth as it enables individuals to conceive of the world and their existence in creative new ways. Books give access to different spaces, enable access to alternative frames of reference and “embrace” all time frames (LTB10 16). They empower the disenfranchised. Kuusisto observes: “Poetry differs from other forms of expression in two essential ways: it does not aspire to tell the literal truth and it can get at the truth with unreliable methods” (“Digressions on Poetry” 198). In “The Books to Come,” books are positioned alongside ‘myths’ not as sources of false and distorted information but as our individual narratives transposed into myths through time. Time itself becomes an illuminating force; the “solarium,” from the Latin for sundial, for example, measures the spaces of time. However, Kuusisto dissolves the intervals of measured time to problematise the relationship between old and new, questioning the point of assimilation when ideas pass into “truth” (“Digressions on Poetry” 198). Kabacinski notes “This oscillation between the mythic or traditional past and the everyday present is emblematic of Kuusisto’s memoir and corpus of poetry” (53). The oscillation is a “transgressive”
movement through time and space which creates a “montage” of words, images, cultural codes, values and perspectives that subvert traditional historicism and disrupt relational thinking (Lilach Lachman 62).

In “The Books to Come,” the reassembled collage reshapes the narrative as a personal and collective memory. Within each repetition of the refrain there is an altering of meanings and language, subtle reinventions that slip from “books to come” to “Books out there” (LTB10 22-24). These modifications are hidden “like secret friends,” and then revealed in each repeated utterance:

The books to come. Likely

To save us
Like secret friends, books to come
Like hopes and intervals of hope,
Books out there
To be read in the hush of days. (LTB10 21-25)

The repetition of “Like” suggests a natural mimetic set of relationships but the tacit rules of the production of the relationship are artificial. For Kuusisto, the potential for books “to save us” is uncertain and sporadic. The message which emerges is that the poet-seer can open our eyes but this does not guarantee future change. The “go ahead” of ever emergent horizons is an extended process of becoming (LTB10 26-28). As such, the imagined texts function as mediators, mutually developing understanding in an almost mystical hermeneutic act of exegesis:

The ripening fruit in the books to come;
The names of imagined children;
The “go ahead”; the “as always”;
The “necessary”; the “needing to cross”;
Not better than your life but the life you will know. (LTB11 26-30)
The “quotation montage” replicates multiple narrative voices and expresses a “logic of composition” in the balancing of refrains (Lachman 67). The spoken language is fragmented into minute parts yet collated in the process analogous to collecting “twigs” (“In our Time” OB55 39). The repetitious listing of binary categories also recalls the linguistic pairings of Kuusisto’s childhood poem “No Name for It.” In “The Books to Come,” the semicolons disrupt the interplay between utterances and suggest a displacement in both time and contexts. The future remains just outside reach as the chronological direction of progress is still, as yet, uncertain. The concluding line-change to the unspecified pronoun “you” emphasises the identity of the reader of the physical poem within the collective group of “us” as included others (LTB11 30). The shifting sense of subject alters our understanding of the subject’s and our own relation to history and space.

Kuusisto makes us confront literature and language as ideas that cannot be fully owned outside of an ongoing collective experience. In the rehearsal of knowledge there is an incompleteness; the certainties of conventional thinking about embodiment and perception are found to be elusive and opaque. Kuusisto states: “I believe that in every blind person’s imagination there are landscapes . . . These are the places learned by rote, their multiple effects of color made stranger by fast-moving clouds” (P63). These enigmatic landscapes are replicated in descriptions which reveal, cover and make strange by de-familiarising and expanding ways of knowing to remind us that what we think we know is often a misdirection of perception and reality.

**Conclusion: “Riders of Dragons”**

This chapter explores the reasons why space is important in Kuusisto’s poetry as a means of enabling him to challenge ocularcentric notions that blind individuals have limited conception of space, perception and embodiment. For Kuusisto, navigation of the spaces beyond the walls, windows and doors of architectural and domestic spaces expands as an unexplored frontier, a
horizon opening out into an infinity of indistinct ongoing possibilities and points of contact with other attitudes and ideas. The space of books and poems provides a vehicle for making blindness visible, making it part of public discourse and challenging inertia.

Like Derrida’s discourse on the concept of “visible in-visible,” Kuusisto demonstrates the fallibility of human perception (Gift 90). Whereas Derrida suggests that objects exist because they are directly visible and then considers how objects continue to exist when placed “under clothing or a veil” becoming invisible, Kuusisto considers how we think we know the original object (Gift 90). He makes us reconsider how we know space, how we conceive space and how we see space. Kuusisto’s poems convey the richness but also the shifting, subjective nature of sensory perception. He articulates how a “blind person experiences a series of veils,” emphasising the dominance and multifaceted stratification of experience over perception (P5). For Kuusisto, “Embodiment is a practice, the willful deployment of language that both makes and unmakes us” (“Crip Poetry”). Through a process of renewal, he reclaims a highly personal language of embodiment, reshaping linguistic allusion and syntax.

To make blindness more visible, Kuusisto reclaims the space for including blindness in public discourse: “Behind all my poems is the vivid assertion that I belong in the public square” (Appendix 2 278). Michalko argues that blind individuals need to be made more visible and understood as active agents in society: “We do . . . make an appearance in the world and we do so to and for others” (“What’s Cool about Blindness?”). In the space of his poems and the spaces of the imagination, Kuusisto constructs rooms which house memories, language and understandings of lived reality. He seeks to represent these moments of experience, and to defamiliarise connections between interior experiences and exterior landscapes, figuring alternative ways of perceiving space through touch and sound.

Any argument asserting that Kuusisto reads space through sound centres on determining in what way space is heard and atypically experienced through blindness. Furthermore, we might ask
ourselves, how can space be seen by what is heard? Seaman observes that Kuusisto “presents exquisitely rendered soundscapes that capture aspects of the world most of us barely register, from the storm of traffic to the cacophony of our myriad machines to the songs of trees” (Booklist). Kuusisto explains his intense interest in focusing on different sounds and the absence of sounds to document both the astonishing and the ordinary. Kuusisto listens to the minutiae, sounds which serve not only “for utility but for sustenance” (E70). In a blog post, Kuusisto outlines his inherent desire to assert some control over the unknown and unexpected:

Let us assume blindness is never static and always takes its meaning in phenomenological terms from movement. Let us describe blindness as ‘Proleptic Imagination.’ Traveling blind is a performance both within normative subventions of assistance and outside cultural denotations of helplessness. Blind travel, taken as performance, is proleptic, both anticipating and answering implicit objections to the concept of blind independence in the very process of navigation. (“Disability, Poetry, and the Three Caskets”)

In the anticipatory space of the “Proleptic imagination” the process of building a new library of words is slow: “I read like a geologist, seeing quickly into the Paleocene acrostic” (P129). The allusion to the paleogene period suggests that he imagines himself like a geologist, uncovering the past, searching for the origins of language and human behaviour through the process of reading and writing.

Writing poetry creates awareness for Kuusisto that “literary writing is understood as an obligation to reach beyond the self” to break the metanarrative of blindness (“On the Probable Death of Empathy”). For Kuusisto, reshaping experience, resisting linguistic inertia and creating poetry is a vital conduit for change: “My spastic eye takes in every word like a red star seen on a winter night. Every syllable is acquired with pain. But poetry furnishes me with a lyric anger, and suddenly poems are wholly necessary” (P65). He argues that within disability studies, poetry can
complicate and de-familiarise, creating a type of imaginative “smoke” that obscures rigid demarcations within epistemologies and unsettles conventional ideas about bodies and space:

Critical disability studies and crip studies seek to destabilize traditional modes of body analysis and affirm (perhaps an ableist trope) a post-static and unreferenced sense of bodies. I sometimes think of classic, normative bodies as vanishing before our eyes like Brigadoon. In this way I relish what [Lennard] Davis calls the end of normalcy. I like to say (because I’m a poet) that I’m not a blind man at all but instead a rider of dragons. The smoke I leave behind is poetry. It suits me. This is disability as epistemological fancy.

(“Disability Poetics: Essay Number One”)

Kuusisto comments on the “ancient Chinese idea that if you wrote a poem, you would disappear in the sky and leave behind a little dragon smoke” (Niord4485). In this image, he recalls Robert Bly’s essay on “leaping poetry” (“Dragon Smoke”). As a “rider of dragons” Kuusisto breathes new fire into classical and contemporary writings, old songs and sayings, refashioning citations, creating new metaphors from the “smoke” and the ashes. His poetry invokes a rich past of writing about embodiment, space and perception but also offers a conception of poetry that is part of an ongoing and innovative tradition.
Chapter 3: “Reshaping the Outline”: The Skin and Spine in Laurie Clements Lambeth’s Poetry

Introduction: MS “my friend and foe”

MS ultimately cannot be forgotten. It is both my friend and foe, intermittent but lasting. If I am an MS activist, I know it is through awareness—my own, and creating it in others—in my teaching and writing, in everyday interactions, knowing that the disease is so deeply linked to who I am and what I do. (Lambeth “Old Friend”)

This chapter explores American disability poet Laurie Clements Lambeth’s episodic life writing verses, “fragmented” prose, and various online free-verse poems and reads them as unique depictions of embodiment. Nine of the fifteen poems scrutinised are from her debut collection Veil and Burn (2008) and a further two poems, “Dysaesthesia” and “Hypoesthesia” are taken from the Beauty is a Verb (2011) disability anthology (Bartlett et al. 178 182). A significant number, however, are obtained from non-print based sources: “A Trace for Jacques Derrida” (Connotation Press), “EXAMINATION: MRI of the brain with and without contrast” and “The Selection of a Child for Illness, A Fable” (“Wordgathering”), “Hypertonia” and “Enjambment” (“Tupelo Quarterly”), are all found in e-magazines and online poetry communities. They demonstrate Lambeth’s commitment to reaching a range of audiences and publishing in a variety of different spaces. Lambeth’s poems re-examine the spaces of the body, interrogating the boundaries of disability definition and focusing on the creative processes of imagination and representation. Her work is concerned with body spaces, external and internal surfaces and layers. It also articulates an intense subjective awareness of the relationship between the self and the world around her.
Through this attention to representing the body in space, the space of the body and the space within the poem, Lambeth creates new spatial metaphors of the body’s surface as an interface between internal and external relationships. Unlike Ferris and Kuusisto who were diagnosed with their condition at birth, Lambeth’s symptoms of multiple sclerosis (MS) first became evident at the age of 17 after experiencing a “numbness that spread up her left arm and down her body” (Alice Walton). Her writings are distinctive, therefore, as they are informed by the change to her physical form and, with each new symptom, reflect shifting perceptions of her embodiment. In Lambeth’s own words, the poems represent interconnected and highly subjective re-imaginings of “who I am” (“Old Friend”). In documenting the intermittent yet permanent and regenerative presence of MS, her poetry enables readers to reconsider and differentiate the manner in which bodies operate, are contained by, and/or interact within different spaces.

In the analysis which follows, I elucidate some of the many ways Lambeth reconstructs embodiment as a veiled, porous, blurred, fractured, hardened shell-like bodily contour which contains a dissipating and numbed psyche. The surface coverings, I propose, are representations of shifting outlines that both overlay and expose the cultural contours that shape her individual embodiment. They draw attention to the relationship between absence and presence that structures Lambeth’s poetry and her representation of disability: they shake, rupture and harden, cover and uncover, blur and dissolve. They are expressive of contact with multiple permutations of MS experience and grounded in a public articulation of the private pain of losing bodily sensation. Lambeth articulates the subjective experience of physical and emotional pain in order to problematise fixed medical and cultural definitions of embodiment. Whilst Ahmed argues that pain makes us more aware of our relationship to other objects, as it is “through the intensification of pain sensations that bodies and worlds materialise and take shape, or that the effect of boundary, surface and fixity is produced,” Lambeth’s poems express a shift in that process (Cultural Politics 24). For Lambeth, the process of knowing objects and spaces through somatic
sensation is one which is intermittent, fluid, alternating between numbness and pain. Her poems represent the invisible nature of pain whilst calling attention to the materialisation of the body’s surfaces.

Studying Lambeth’s poetry, I contend, contributes to the debate about the boundaries of medical, social and cultural definitions of dis/ability. Sherry Peters comments that whilst there is growing acknowledgement that the definition of what it means to be disabled is influenced by a variety of socio-historical, geopolitical and cultural contexts, there needs to be a greater recognition of individuals with “invisible disabilities” in public spaces (26). E.J. Samuels’s more recent observations indicate there is still a “politics of visibility and invisibility” concerning the episodic nature of some disabilities (233). She uses the term “nonvisible to indicate the condition of unmarked identity and invisible to indicate social oppression and marginality” (252). Lambeth’s poetry resists language that ignores the “unmarked” by creatively blurring and challenging binaries that attempt to define the limits of in/non visibility.

As Lambeth observes, to focus solely on the narrative of MS disability, is to “lean towards the objectifying gaze” (“Paul Guest: Review of My Index of Slightly Horrifying Knowledge”). Whilst her poetry is part of a movement by people with MS that strives to gain greater recognition, Lambeth explains that her priority is to focus on the power of the imagination and to write poetry that speaks to a wide audience. This is work, she suggests, that “testifies to the strength of the poet and the strength of poets with disabilities” (“Marketing Disability”). She adds “I would hope to at some point be seen by readers as part of the disability movement, some refraction of it, but not at its center … Moved instead by absolute fidelity to the quirks and obsessions of my imagination” (“Marketing Disability”).

The following three sections all explore Lambeth’s metaphorical and structural representations of the body as a layered, fragmenting and complex surface of dissipating walls and outlines; surfaces that variously invert, harden and/or enfold as if protecting rather than
destroying the soft, internal tissues. As Jean Starobinski and Frederick Brown observe, the skin can be understood as “In between the outside and the inside, the contact surface - whether it be membrane, film, or skin - is alike the place of exchanges, of adjustments, of sensory signals, and the place of conflicts or wounds” (342). The skin, therefore, is typically depicted as the body’s outer surface, the natural barrier between the individual, the environment and the external objects occupying these relational spaces. I want to demonstrate that Lambeth’s poems complicate the notion of a single epidermal layer and expand the surface space of the body to incorporate ambiguous, blurred internal and external surfaces which move fluidly between intersecting and disconnecting.

I suggest that Lambeth confronts the limits of language and seeks to create new metaphors of the skin and the body as expressions that offer “something else” and convey “experiences related to vision loss and fear of memory loss” so that they can be better understood (“From Metaphor to Metamorphosis”). On her distinctive use of metaphors, she says: “I felt that metaphor played a vital role in conveying physical experience or biology” (Appendix 3 286). From this perspective, she reconceives the internal spaces of the body and reshapes the exterior surfaces of her body through her poetry, using language and metaphor in particular in order to regain some control over her own narrative:

I found myself also turning to Gayatri Chakravorti Spivak. The idea that certain alien experiences could never be understood by the mainstream makes me think of temporarily non-disabled people’s perceptions of disability; they don’t want to listen or think differently, so communication of physical sensation is nearly impossible . . . But of course my creative work insists that it must be possible, and I try, hoping for a reader who will absorb the language and dwell in the poems. (Appendix 3 286-287)

Lambeth’s poetry provides opportunities for thinking more broadly about how disabled embodiment is constructed differently in different spaces. In complicating and challenging the
conventions of skin theory, her poems open up ways of asking readers to think about race, gender and other “alien experiences,” to “absorb the language” whilst taking the opportunity to “dwell in the poems” (Appendix 3 286-287).

At first glance, the titles of her poems appear to immerse readers in verse which reinforces rather than challenges traditional medical diagnoses: for example, “Dysaesthesia,” the medical term defining unpleasant abnormal altered sensation; “Hypertonia,” the rigidity and spasticity of muscle tone; and “Hypoesthesia,” a reduced sense of touch (Mosby’s Medical Dictionary. 878, 882, 574). However, these medical “mechanistic descriptions” are based on a biomedical model of disease that are then expounded upon, reinterpreted and refashioned to expand understanding of lived experience, moving from the “what” of medical science to the “how” and “why” of creative inquiry (Arturo Casadevall and Ferric Fang 3517). Contesting restrictive and reductive definitions of disability, Lambeth documents the stages of MS prognosis, its fluctuating symptoms of numbness and pain, its intermittent, unpredictable development, elucidating its hidden nature. She describes how “There is indeed a chaotic quality to a disability that shifts and interrupts, leaves and re-enters one's life in new, surprising ways that at once echo earlier experiences and carve out new notches into the body,” charting the progression of symptoms (“Reshaping the Outline”175).

Termed a lifelong chronic condition, MS affects the transmission of nerve signals between the brain and spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance. This neurological failure is a disconnection felt between the brain and the body. Moreover, the condition is considered an autoimmune disorder where the body’s immune system fights against itself, causing damage to healthy cells and natural defences turning hostile and inward (Neil Scolding and Alastair Wilkins 13). Her poems articulate the self-ingesting, chaotic somatic experience of living with this
relapsing-remitting degenerative condition in order to make the hidden reality of MS more visible.

Unlike Ferris’s asymmetric outline and Kuusisto’s appendage of white cane and/or guide dog, Lambeth’s external appearance gives little indication (for the most part) of atypical embodiment and masks the changes in physical mobility that disrupt her navigation of different spaces. In addition, emphasis on outward appearance fails to disclose the phenomenological and emotional dimensions of her body’s internal neurological disconnection. According to S.K. Toombs, this sense of detachment, linked to the experience of illness, “represents a distinct way of being” and is “characterized not simply by bodily dysfunction but by a concurrent disruption of self and the surrounding world”; the “malfunctioning body” presents itself as an oppositional force that creates a “sense of disorder” (“The Body in Multiple Sclerosis” 127). Toombs attributes the “body disruption” engendered by loss of mobility to changes in the “character of surrounding space, an alteration in one’s taken-for-granted awareness of (and interaction with) objects, the disruption of corporeal identity, a disturbance in one’s relations with others . . .” (“The Lived Experience of Disability” 9). My chapter will explore how Lambeth’s poetry creates fresh metaphorical representations of marginalisation as “disruption and disturbance”; representations of alternative bodies navigating public and private spaces; and spaces in and outside bodies, oscillating between soft and hard surfaces that rupture and expose when intersecting at the meeting points of societal practices (“Lived Experience” 9).

The emphasis on re-imagined outlines demarcating the interior and exterior spaces of the body is characteristic of the poems analysed in Section One: “Invisibility and Erasure.” The poems “Enjambment,” “The Selection of a Child for Illness, A Fable” and “EXAMINATION: MRI of the brain with and without contrast” are chosen because of the interesting ways in which they chronicle the “unravelling of her body, including the poet’s sight, her ability to walk and her memory,” in a public articulation of the private pain of losing bodily sensation (Northen “Book
Review: Veil”). They combine the representation of embodied form with a sense of a dissipating, fragmenting and erased self. Their content and form draws attention to the unpredictable relationship between absence and presence that structures her representation of embodiment.

Section One explores how Lambeth crip[s societal and media representation of the ideal body, often mocking the role of medical figures who surgically impose institutional and cultural ideals of normalcy by reconfiguring physical bodies. For example, in a playfully poetic re-appropriation of one of the most famous cinematic depictions of constructed embodiment, “Case History: Frankenstein's Lesions” (VB33-36), Lambeth explores both her own and broader societal attitudes to embodiment. Typically, the monster created by “Dr. F.” is a figure that exemplifies all bodies that fail to conform to stereotypes. The play on the name “Abby Normal” is an allusion to Gene Wilder’s parodic film version, where Igor mistakenly substitutes the brain labeled abnormal. The humorous reference points to the ineptitude of medical practitioners:

Mine was the one jar that did not break,
and I sloshed against its walls with each lurch
of the hunchback’s pitching, tilting ramble.
Nobody sliced me; I was too precious
whole, tight bundle of tissue disembodied,
“just resting, waiting for a new life to come,”
said Dr. F. He didn't know how much I’d like
to rest, stay out of bodies for a while. (VB33 17-24)

The patient-speaker’s viewpoint is expressed as internalised thoughts disconnected from the spoken comments of “Dr. F.” (VB33 23). This aspect is conveyed through the conversational tone as the voice of a disembodied brain, one held captive in a jar as a separate “bundle of tissues” awaiting transplant (VB33 20). The speaker’s wishes are ignored, or rather, not even
sought. In exploring and representing this, the verse depicts the failure of many conventional narratives, myths and cinematic depictions to engage in discussion of complex embodiment. It plays with the Cartesian notion that the mind is separate from the body which is complicated by the numbing disconnection of MS.

Much of Lambeth’s writing, like “Case History: Frankenstein's Lesions” focuses on the detached interiority of the body and the senses (particularly of sight and touch) rather than detailing experience from the perspective of external observation of outward appearances. She explains:

I was struck by the ways images from popular culture impose themselves on our ideas of physical — felt — experience. For me, the trigger moment occurred when, during a flare-up, I felt as though I walked like Frankenstein’s monster, tipping, heavy-footed, off balance and then realized that the image I imposed upon myself was one built from external observation: I was “feeling” what I had seen enacted on screen, and so I then set out to imagine cinematic representation through sensation (“Reloaded: Introductory Remarks”).

In her poetry, she both acknowledges and challenges societal pressures to refashion and perfect the outer contours of the body. Instead, her poetry represents individual, sometimes fleeting experiences and insists not all bodies and brains perform in the same way. Alan Fogel argues that we must be wary of viewing “the mind as a disembodied relationless computational machine, as an objective thing inside the head” (4). In contrast, Lambeth redirects the gaze to the interior and affective spaces of the body in her poetry.

The dynamic connection between poetry and illness represented in Lambeth’s writing is expressed through a fluid approach to language and poetics and, increasingly, a focus on questions of interdependence. Lambeth states that for years medical symptoms of MS did not feature in her poetry, “but then it did and my experience of disability deepened, or vice versa.
They helped each other along” (“Reshaping the Outline” 176). These observations suggest a more complicated connection with MS than readers might have expected. She comments on the futility of adopting a negative viewpoint: “If I hated MS, and MS is in my body, then I would hate something in my body with its blurry, numb edges, its droop and drag, its slackened strength, its brain lag, and I would, in essence, hate myself. I don’t want to fight that fight…” (“Fatigue”). Here, even in prose, the alliterative and sibilant list of multiple symptoms of “droop and drag . . . slackened strength” is characteristic of the way Lambeth uses language to build complex, cumulative descriptions which slide into each other, drawn out on the tongue by the assonance of long vowels (“Fatigue”).

Lambeth catalogues supposedly binary symptoms which imperceptibly slide from one another; her writing blurs the lines, the “numb edges,” and explores the liminal space between the presence and the absence of MS (“Fatigue”). Reference to the lack of sensation, the “brain lag” and numbness, communicates an understanding of the way MS affects the transmission of nerve signals (“Fatigue”). In Section One, I examine how Lambeth represents lesions in areas of rupturing tissue as spatial voids between the brain and spinal cord. Lesions, wounds which lie hidden inside body spaces, disconnect her from physical sensation and cultural connections. Her comment that “I don’t want to fight that fight” reminds us that Lambeth rejects any notion of turning her experience into a celebratory narrative of overcoming illness (“Fatigue”). Instead, I propose, her inward gaze gives voice to a subjective representation of lived reality in order to make her overwhelming sense of cultural invisibility into a visible presence on the page.

In Section Two: “Body Armouring: Shell Coverings and Second Skins,” the focus of analysis shifts from the imagined interior spaces of the body to refashioned exterior spaces. Imagery of outer casings, clothes, shells, pearls and bi-fold molluscs convey body contours as hard outlines, as external surfaces which protect the vulnerable interior psyche. For example, “Hypertonia,” with its clam imagery and “Symptoms,” with its trope of a whalebone corset, both
represent shells and clothing as metaphorical coverings. The pearl trope in “Retrobulbar” (VB66) and “The Merle” (VB68) suggest how many of Lambeth’s poems equate the defensive layering of the skin with the dense amalgamation of shell-like cells and coverings of hardened, translucent fabrics. I propose that the hardening of the body into clam-like shape is a metaphor Lambeth uses for conceptualising control, reclaiming language and reshaping the contours of embodiment. In “Retrobulbar” Lambeth depicts the formation of a retrobulbar abscess which occurs behind the eyeball as a symptom of MS:

    as though the lesion somewhere behind the bulb —
    optic nerve, optic chiasm, orbit
    of fluid under bone — was a pearl
    rolling its weight behind and above my eye,
    there in the socket. (VB66 1-5)

The pearl motif is used as a metaphor for the damaged lesions in the eye caused by MS. The lesions are surrounded by ossifying tissue in the same way that a pearl is created in response to an irritant invading the space of the oyster. The spherical shape of the eye and pearl outline is suggested figuratively in the repeated “o” phrasing, particularly those of “optic,” and “orbit” (VB66 2). The eye’s interior lesion is formed from cells binding and “rolling” in the “chiasm” of space (VB66 2). The “rolling” movement emulates the pearl’s formation, suggested by the narrator’s choice of “behind,” “under” and “above” (VB66 4). The repetition and placement of the phrase “behind,” in particular, evokes the “fluid” process of wrapping and enveloping the hardening pearl-sac nucleus forming inside the eyes (VB66 4). Juhani Pallasmaa argues that “The very essence of the lived experience is moulded by hapticity and peripheral unfocused vision. Focused vision confronts us with the world whereas peripheral vision envelops us in the flesh of the world” (10). By contrast, Lambeth’s translucent pearl is aptly opaque, rendering “experience” as neither invisible nor wholly visible “as flesh” of itself and “of the world”
In a different context, Lambeth’s pearl imagery reappears in “The Merle,” as representations of white maggots eating the infected flesh of a dying dog. The image is at once unexpected and unsettling:

one of those cattle herding dogs
from another ranch, come to our farm
to die. *We don't want you; this is not heaven,* I told the dog. *Go back home.*

She slowly rolled sideways to show her pink belly, a bright underside slit up
the center, ravaged by maggots. Pearls,
the gaudy kind, adorning the living. (VB68 3-10)

As pale-skinned reminders of death and decay, these maggot-pearls are represented as rich jewel-like appendages “adorning” the external surfaces (VB68 10). Eating away at the torn flesh, the parasitic harbingers of mortality serve as superficial, outward signs of wealth and beauty. Yet, from the wounds of the flesh, the maggots transform into pearls. They are de-familiarized as a “gaudy kind,” tasteless rather than pure, internally generated pearls, forming an aesthetic beauty from within (VB68 10). On one level, pearls are emblematic of a defensive shell within a shell - a double layer of surfaces. On another, the pearl-lesions can be equated with the notion that optic neuritis is an unsought gift: one that emerges from an irritant into a thing of beauty. These pearl and shell fabric tropes, however, are not simply manifestations of optical experience or representations of variants of visual practice. For Lambeth, they signify the displacement and interrelation of skin and subject, the synaesthetic mesh of memories and events accumulated as imprints of observed cultural objects and relations that form the story of her embodiment.

Section Two, therefore, explores various representations of sensory and psychological shell-like
defence mechanisms which function as metaphorical modes of protection against the physical pain and emotional fear of losing one’s sight, the ability to walk, and the acutely felt fear of losing cognitive memory and language.

In expressing the vulnerability of a single, particular body, Lambeth also communicates the inherent vulnerability of all bodies. In Section Three: “Writing and the Exposure of the Body,” Lambeth charts the affective, emotional pain caused by the inability to sense her partner’s touch and expresses this through fractured structural forms, staggered sentence layout and fragmented, enjambed lines that suggest the notion of body contours touching and yet remaining spatially and emotionally separate. Through my readings of “Dysaesthesia,” “Hypoesthesia,” (VB44-45) and “Coming Down” (VB1-2), I explore Lambeth’s interest in disabled, reconstituted bodies, in exposure of the self, and in a complex, layered schema that challenges white, Western, male, normative conceptions of embodiment.

For Lambeth, revealing psychical, emotional and physical scars is a necessary part of a healing process. As Ahmed states, the process is one of exposure: “Healing does not cover over, but exposes the wound to others: the recovery is a form of exposure. The visibility produced by recognition is actually the visibility of the ordinary and normative or the visibility of what has been concealed under the sign of truth” (Cultural Politics 200). Whereas Ferris’s surgical scars in “Scars” are a visible mapping of “memory/ tough and carried on the skin,” Lambeth maps numbness and pain as invisible emotional scars that expose interior vulnerability (Kuppers “Scars in Disability Culture Poetry” 145). It is this emphasis on making the invisible visible which characterises Lambeth’s thinking and her poetry:

I imagine this liminal state of visible and invisible disability brings me to poetry. I want to investigate it because the experience feels so entirely internal, reminding me that others do not understand my physical state at all unless I share it. Sometimes I don’t understand it either, so I bring the question to the page and the poem offers answers I
may not have anticipated. So the poem (or essay) is both a place I go to express disability encounters or changes and to find out what they might mean (Appendix 3 280).

These comments emphasise the tension between the private “entirely internal” knowledge of disability experience that poetry gives the space and agency to expose and make public. They express these “encounters” and “changes” as fluctuating, intersecting meeting points between the “liminal state” of being seen and unseen. With this in mind, her poems can be read as imaginative spaces revisiting conventional notions of embodiment in order to present wider audiences with alternative viewpoints that question both stereotypical ideals of body form and de-familiarise the boundaries of disability.

In Section Three, I show how Lambeth’s poetry experiments with representations of real, therefore imperfect bodies, to disrupt normative ideals of embodiment. The tension between oppressive external forces and the desire to protect or retain an inner self is conceptualised in “Dysaesthesia,” “Hypoesthesia,” and “Coming Down.” The tension resides in the disrupted spaces of the poem: spatial fissures between words and enjambed lines are made by “forced caesuras within each line” where natural breaths are interrupted to mimic how “the body is taken over by something outside of its control” (Christina Scheuer 167). This is given visual expression through the chiasmic spacing of words in parallel columns in “Seizure, or Seduction of Persephone” (VB13-14). The poem provides a useful introduction to the ways in which many of Lambeth’s poems convey a dynamic poetic “adjustment of form to content” (Northen “Book Review: Veil”). Her works often feature internal spatial voids which replicate the skeletal spine as a “gutter down the middle of the poem” (“Dialogue on Disability Poetry”). The technique is one Lambeth attributes to May Swenson and she similarly experiments, noting how a central “gutter” brings “energy and a kind of speed to my poems, while still highlighting rupture, between the ill speaker and her beloved, or between the speaker and her disemboding sensations” (“Dialogue on Disability Poetry”). The “rupture” articulates the fluid complexity of
embodiment as a shifting metamorphosis, simultaneously merging and erasing conventional and unconventional notions of outlines. It exemplifies complex representations of surfaces that simultaneously cover and expose.

In this manner, “Seizure, or Seduction of Persephone” demonstrates Lambeth’s technique of unifying subject matter with poetic form, drawing on the mythical figure of Persephone. The goddess temporarily inhabits the underworld, the realm beyond the veil, then returns renewed as a symbol of rebirth and transformation. Her disappearance and re-emergence, presence and absence from the surface of the earth, intersects with images of shattering earthquakes and volcanic seizures, represented as intermittent MS symptoms which break “through the skin” surface as muscles thrust and spasm:

I convulsed so hard I broke
open, broke the earth,
erupted and pushed out
a narcissus by the roots.

It doesn't matter where
the flower broke on my body,
through the skin, a pimple,
my head, or the belly.

I could not tell you.
What I can say is this:
my limbs flailed and seized (VB13 1-11)
The symmetrical, perpendicular, two-part visual structure conveys the seismic movement of tectonic plates, a rift shifting under a hidden pressure before erupting to the surface. The spinal split is emblematic of liminal disjuncture, a breaking of body surfaces both inside and outside and in between. The key image of “shifting of earth’s plates” represents detachment, the white space caesura graphically mirroring numbness as void of sensation, an absence of connection between internal and external surfaces (VB13 16). As Scheuer notes, “the line as the seizure is presented as a shattering of both the body and the earth” (168). The body, however, like the mythical Persephone, emerges liberated in a fragile liminal space. In this way, Lambeth’s imagery emphasises how we are immersed in a long history of myths, narratives and literary conventions which shape perceptions of embodiment. At the same time, however, it shows an alternative reality fashioned out of a seismic destruction of our histories in which individuals break through barriers of institutional, environmental and societal imprisonment and oppressions.

The language of earthquakes used here is not an isolated example. Lambeth’s blog entry uses similar imagery to describe MS symptoms which “flare a few weeks after an initial, two-month eruption, just to remind me I had MS, and sometimes they wouldn’t return for years. Their epicentres often changed. The central nervous system has many fault lines” (“Identification”). The representation of geophysical vibrations and seismic disturbance is equated with the force required metaphorically to shatter rigid notions of embodiment. In this way, Lambeth illustrates how the internal (private, biological) and external (cultural) influences are not integrated. In the analysis of her work in Section Three, I demonstrate how this type of creative interplay of imagery and form develops a unique mimetic representation of the changing, unstable physiology of MS which, when exposed to societal gaze, figuratively breaks through the confines of restrictive definitions of disability.
Lambeth’s work responds, I argue, to Garland-Thomson’s plea to enhance understanding of cultural concepts of disability, “our relationships with one another” and the “experience of embodiment” (“Integrating Disability” 4). It represents a creative contribution to a field of thinking that helps to challenge and expand understanding of dualistic constructions of dis/ability binaries, complicates relationships between racism, gender and prejudice and, as Phil Smith notes, “creates opportunities for justice, equality, and empowerment” (“Whiteness, Normal Theory”). Lambeth’s concern, she says, is finding new ways of giving voice and specifically, exploring “how a poem might expand perception in ways that people never expect” (“Dialogue on Disability Poetry”). The interconnectedness of MS as “both my friend and foe” is at the fore of her writing; Lambeth’s works suggest a dynamic relationship between poetic form and subject and a desire to express a unique understanding of her own body’s place in the world (“Old Friend”).

Section One: Invisibility and Erasure

The main poems analysed in detail in this section, “Enjambment,” “The Selection of a Child for Illness, A Fable,” and “EXAMINATION: MRI of the brain with and without contrast,” are examples of how Lambeth communicates the experience of marginalisation as a person with MS. The poems explore the invisible presence of MS and how some disabilities remain hidden, separated from mainstream concerns as if a gauze-like fabric conceals them from the gaze of others. The content, structure and subject of these poems conveys the episodic experience of MS as one of unpredictability, disconnection and erasure of the sense of self. Like Ferris and Kuusisto, Lambeth also plays with internal and external outlines to connect content with form, crafting “each poem into a shape that reflects the poem's tone and voice and sometimes its subject” (Lambeth “Dialogue on Disability Poetry”). Mapping her body’s relationship with the
external world is, she says, “like going off margin, if the sense of the poem is right for it. But shapeliness in any form is important for me as a poet, whether a poem is in long line couplets, blank verse, regular stanzas, or in a sort of limping quatrain-tercet-quaternion form, or in short lines” (“Dialogue on Disability Poetry”). Her poems, therefore, invite us to consider the question posed by Mary Oliver: “How can the content be separated from the poem’s fluid and breathing body?” (3).

The free-verse narrations, “Enjambment,” “The Selection of a Child for Illness, A Fable,” and “EXAMINATION: MRI of the brain with and without contrast,” have been selected to explore the many ways MS informs the poet’s unique relationship with her body, its interior and exterior surfaces, and with the spaces around her. As Scheuer notes, “Lambeth's poetry considers how symptoms of MS . . . change the way that she perceives the world, thereby altering her relationship to social space and to her own artistic expression” (158). The poems examine the notion of disabled embodiment as one needing to be redrawn, erased or corrected to fit an alternative aesthetic ideal. The poet herself remarks that MS “altered my perception of my body’s place in the world, as though the outline of what I could call ‘me’ was a broken line, permeable and wavering” (“Reshaping the Outline” 175). By examining Lambeth’s representations of “broken,” “permeable” and “wavering” outlines, I argue that she challenges ableist conceptions of a “stable and coherent identity and body” by exposing the limitation of such fixed notions of self (Shildrick 2).

Lambeth’s fracturing of poetic content and form, I suggest, provides a figurative representation of how the disabling nature of chronic illness is often overlooked because of its invisible neurological form. Whereas Lambeth’s symptoms are masked or mistaken (as drunkenness, for example) in public encounters with others, Ferris’s physical disability is hypervisible. Yet, paradoxically, Lambeth’s experiences make her hyper-aware of perceived interior and exterior otherness: “living with numbness opened my perception of what is me and
what is outside of me” (“Laurie Clements Lambeth”). Her work explores and expands ideas of an invisible, erased embodiment which test the boundaries of definitions of what is a body and what is a poem. Her blog entry, “Scene from the Steeplechase: The Fallen Jockey” exemplifies the way in which her poems merge and layer the invisible shadow-like presence of MS with the narrator’s sense of a dissipating erased identity. The ekphrastic prose analysis of a painting by Degas explains how the painter’s correction of an error in a horse’s anatomy leaves the original mistake still visible as a “shadow-leg” (“Scene from the Steeplechase”). For Lambeth, the rubbing out process replicates an effacing of the sense of self:

    The shadow leg—that’s my leg. That’s my movement: blurred, dark mistake. A correction made to look intentional.
    Surprising I find it here in painted shade. In animated mistake and the vigor of correction.
    But didn’t my stride glow with its own light, my foot’s wavering motion? (“Scene from the Steeplechase”)

The intermittent symptoms of MS are expressed as a ghostly shadow presence, like an additional assemblage that not only alters the contours of the body but also the way in which the body navigates space. As a metaphorical third “leg” it does not have a permanent place, and its temporality is uncertain: the speaker hovers in states in between, unsure of when the narrative might change (“Scene from the Steeplechase”). Indeed, the rhetorical “But” questions why the body is perceived as a “dark mistake” in need of correction; asks why the original signifying contour and “wavering motion” is to be erased when it has a “glow” and beauty of its own (“Scene from the Steeplechase”). Lambeth’s spatial metaphors explore different ways of interrogating how bodies perceived as a “mistake” - in need of medical correction and erased from societal consciousness - also have a “glow” and beauty their own (“Scene from the Steeplechase”).
The title of Lambeth’s collection, *Veil and Burn* sheds light on her broader conceptual framework which sets out to uncover personal experiences of MS and to allow for a form of poetic agency that resists erasure from both able and disabled worlds by stripping back the metaphorical covers which, like Kuusisto’s shadows, veil our sight. Metaphors of space as veils, fabric coverings, exposed contours, photographic film and surface screens are all employed in Lambeth’s articulation of the body’s visibility or invisibility in space. These spaces unexpectedly shift, functioning sometimes as a mediating cover, a porous surface, a transparent film or filtering as an optic lens. They emphasise the fraught nature of representing invisible disabilities by drawing attention to the process of looking.

Moreover, Lambeth’s concept of the lens as veil recalls Kuusisto’s comment that “often a blind person experiences a series of veils: I stare at the world through smeared and broken windowpanes” (P1). Lambeth’s adoption of the trope draws on her own experience of visual impairment as she wears coloured lenses to ameliorate fluctuations in her optic neuritis: “My amber-tinted contacts and glasses cut most glare, pain that never quite left after optic neuritis . . . My vision is literally colored by my disease” (“Old Friend”). Kuusisto writes about the horizons that merge and dissolve, observing “My form of blindness allowed me to see colors and torn geometries . . . I saw no distinction between sky and ice” whereas Lambeth writes about the loss of somatic sensation (E3). At one point she states: “Since I couldn't feel the difference between fabric and a hand on my leg, I began to see the world more abstractly” (Walton). The “fabric” veil, I suggest, is figured abstractly as an ambiguous spatial outline, the interstitial meeting point between the body and other; the liminal space between the interior and the outer surfaces of the skin; and the boundary between the locations the various speakers inhabit.

The motif of the skin as veil is presented in several prose interjections related to perception in Lambeth’s poetry, documenting the gradual and periodic deterioration of the narrator’s vision. These prose fragments juxtapose the collection’s verse, functioning like
episodic events and as Lambeth reiterates, “their positioning . . . and their spareness are what I feel bring the book together through tension—what can and can’t be sung” (“First Book”). The prose poem in the collection, named “[Gauze Fragment]” (VB39), suggests that even the title itself is partly hidden; it occupies space only as an aside as indicated by the use of brackets containing ghost-like italics. Yet all reference to the title then disappears from the prose poem’s final printed location. The title exists only as a memory, a remembered presence:

In Hollywood’s golden age, the camera was often veiled by a thin piece of fabric to dissolve any harsh features or wrinkles in close-ups. The cameraman burned cigarette holes into the fabric to bring the eyes to sparkle. I have a feeling that my vision is something between the veil and the burn, or that it alternates between the two. (VB39 1-5)

The image of the gauze emphasises the thin, translucent quality of an open weave fabric used for medical purposes. The material is especially useful for dressing wounds where other fabrics might stick to the surface of a burn or laceration. Medical gauzes can be covered with a plastic porous film to prevent direct contact which further minimises wound adhesion. For Lambeth, the image alludes to the scarring of tissue caused by optic neuritis and is a representation of “vision loss” (“First Book”). Lambeth notes, “The title Veil and Burn . . . enlarges the concept of “[Gauze Fragment],” which seeks representation of my vision loss in an old Hollywood trick: veiling the camera lens to soften wrinkles in close-up and burning the veil with a cigarette to let the actor’s wet eyes sparkle through” (“First Book”).

References to Hollywood idols, cinematic photography and screen projectors recur in Lambeth’s poems and foreground the relationship between vision, body and technology. Here, they also highlight the dichotomy between fabricated, superficial appearances, the Hollywood dream of fame, and aesthetic ideals of beauty and everyday reality. The photographer’s veil masks the skin’s surface, covering defects from view like a second skin, while the eyes of the
observer are deceived by hidden tricks of the trade. Significantly, the word veil also alludes to the technical term for the fine membrane, the pellicle surface of camera film. It is the thin coating which serves as the basis for the sensitive chemicals on the paper-surface, the edge that is to receive the photographic impression. The membrane puts external stimuli and internal instinctual pressures on the same plane, flattening out their differences. Between the eye of the camera and the projected screen surface the interstitial space exists, testing the limit of the outlines, their beginning and endings. Its flattened space between the surface skin of the internal camera lens and the external photographic paper highlights the proximal relationship of the printed image and the skin surface of the projected individual.

Laura Marks’s concept of “haptic visuality” in film studies emphasises the significance of the relationship between “perceiver and object represented”; she argues that the viewer is able imaginatively to “project onto the object” (xi). Haptic visuality involves “more senses than vision alone” as it connects the senses of vision and touch (187). Unlike optic visuality, the viewer’s body is “more obviously involved in the process of seeing” (187). For Lambeth, the motif emphasises the disconnection between object and protection when touch and vision are impaired. It functions as a representation of the experience of looking outward through the internal, damaged optic nerves, at the site of a two-dimensional interface. The speaker’s reality “alternates,” fluctuating as “something between” relapse and remission; in the interstitial space of the “veil” and the “burn,” the haptic interface between states of being is blurred and ambiguous (“[Gauze Fragment]” VB).

Lambeth’s poems depict the hidden nature of some disabilities which blur the edges between the inside and outside and replicate the experience of altered perception resulting from ocular scarring. Distances between points of contact confuse the subject-object divide: “My perception of my entire body’s position within the blur and hum surrounding me, where the ‘me’ began and the cushion of space around me ended, disintegrated. People and objects—walls,
even—would all of a sudden enter my frame of vision, my space, uncomfortably close” (“Toddler”). In the act of looking, objects and surfaces suddenly appear as spatial perspectives alter and distances between sites dissipate.

Like many poems in her collection, “Enjambment” demonstrates how the concept of the invisible presence of MS can be imaginatively represented. The title is a reminder of Ferris’s seminal article, “The Enjambed Body: A Step Toward a Crippled Poetics” (discussed in Chapter 1), which advocates celebrating asymmetric bodies. He argues that body metaphors “abound in discourse about poetry. From the basic meter to discussions of language and form, from the long, skinny the dactyl to the poems beating heart and loping flesh, the body is an important image in poetry, it is also an important image of poetry”(219). In choosing such a title, Lambeth makes a direct connection with discourse on physical disabilities, MS and other invisible disabilities. It situates her poetry in the field of disability studies, emphasising the tension “between how episodic disabilities are embodied versus the manner in which ‘disability status’ is legislatively constructed” (Ernie Lightman et al.). Further allusion to Ferris’s work is made in the final line of Lambeth’s poem, “Enjambment.” The phrase “I keep a foot in each world” conveys the experience of embodiment bestriding the two worlds of disabled and non-disabled medical categorisations, hovering as an asymmetric ghostly presence between both spheres (12). Ferris’s poem, “Pater Noster” is recalled here, as Ferris’s speaker perceives their body straddled between opposing landscapes of reality and imagination, living inside the space between the hospital and the outside community “in the narrow space/ between two worlds” (HP34 2-3).

Whereas Ferris chooses to represent his poetic speaker as existing in an imaginative interstitial landscape, Lambeth does not. She is placed there, she feels, by being excluded and marginalised because her condition “doesn’t follow any expected chronological illness narrative” but encompasses “periods of stillness—of movement, of vision, of mind, of sensation—interspersed among moments of free motion” (“‘Chronic Care Broken Leg’ by Keith Carter,
Photograph”). The speaker in “Enjambment” contemplates how one moment she can move easily around her home but the next she meets with muscle resistance. The knowledge of how to walk, Lambeth observes, comes from learned lessons in the transmission of neurological messages which “reside in the memory of my cells, passed down from one cell to another, like stories” (“Incline”). However, “Enjambment” describes how in these moments of an absence of cognitive neurological connection between mind and muscle movement, there lingers the “shadow” of a former presence:

(hold wall, heel first, steady now, lift the next). My gratitude
at such moments is not for the walking, that easy

grace. It’s for the shadow, that other gait hovering around
my frame, a faint, wavering outline, staggering dragged

water-edge purling behind. How can one measure time or space? (lines 5-9)

The intermittent nature of MS as a condition is represented here in the abstract images of opaque borders, torn lines and disconnected surfaces of the poem’s erratic outline, in the enjambed gap between “easy” and “grace” and the drop to the detached image of water rippling behind (6-7). These spatial representations evoke the disparity between being included and excluded from the disabled community: the boundaries and edges of the two worlds are indistinct, shadow-like, “hovering” as a liminal presence (7). The speaker marks the contraction and permeability of her “frame” in its “wavering outline” as it unfurls, dissolving the spaces in and between “purling” contours (8).

This image is given clarity elsewhere when Lambeth remarks on the dissipating, blurring of sensations that characterise the experience of MS: “my consciousness of that blur came after I felt it. I felt an absence of sensation that opened my body up to the environment around me. I
became permeable” (Appendix 3 281). The verse structurally emulates a varying, asymmetric gait, visually presenting an image of uncertain, halting progress. The broken lines falter with the hiatus of each caesura. Times of confident physical movement are conveyed by the verb “stride” which is replaced by the adjectives “wavering,” “staggering” and “dragged,” indicative of the weakening movement of the leg in stages of remittance and replicated in the heavy drag of the consonants “g” and “d” (8). The speaker identifies within the outline a “shadow,” a blurred, muted outline, an incorporeal being at once expressive of an absence and an erasure of presence (7). Old symptoms continue to haunt; new ones inevitably arise.

Lambeth juxtaposes lines that are broken, unbroken, and a synthesis of both, depicting the inconsistent nature of her condition. She captures the difficulty of navigating spaces when she observes: “If I say things are going downhill, slipping through a downward spiral, it’s clear that the grade of my descent, metaphorical or actual, is fraught, steep, confusing . . . Going downhill is an unstable act of speculation” (“Incline”). This instability, I argue, is what makes her seek alternative expressions of movement as she negotiates familiar terrains that suddenly transform into unfamiliar gradients. On another occasion, she observes that “my feet are known to swim, even in their shoes, suddenly strangers. And it’s not necessarily my feet’s fault. They’re not lazy, just forgetful, unable to communicate” (“Vertiginous Patterns”). The body and brain fail to “communicate,” their neurological lines of transmission unable to intersect with other surfaces.

This numbing of internal and external sensation and sense of disconnection features in many of Lambeth’s poems. For example, it is replicated in the detachment figured in “The Selection of a Child for Illness, A Fable.” The poem’s theme emphasises how all bodies decay over time but for the most part, we remain ignorant as to when that reality will occur. As a “Fable,” the poem’s moral lesson exemplifies the truth that outward appearances are deceptive; skin mediates but also conceals reality. According to Didier Anzieu, the skin “fulfils the function
of supporting the skeleton and muscles” (106). It functions by protectively “covering the whole of the body and having all the external sense organs set it” (Anzieu 109). However, Lambeth's depiction here emphasises how the skin veils illness, hiding the body’s interior secrets. The subject matter recalls the typical childhood experience of being measured against lines made on a wall as marks of progress and growth. The speaker’s experience is atypical: the body conceals interior lesions which literally and figuratively chart the hidden progression of MS. The knife cuts indentations into the wall but these are representative of the invisible progression of the illness, as if the wall’s hardened surface is signifying an outward pockmarked skin of visible imperfections:

They stood each child,
one at a time, back against
the wall with uneven pocks. (lines 1-3)

The anonymity of the “They” in the opening stanza gives an impersonal tone, distancing the connection between parents and child (1). The effect creates a sense of disengagement as if recalling actions as impartial facts rather than subjective sensations or emotions normally associated with parental-child bonds.

Shifting the viewpoint from subject to object enables Lambeth to articulate different stages of this ritualised rite of passage and conveys an increasing sense of emotional detachment. The speaker appears as an objective observer, distancing the childhood event from its current relation to the reflective adult voice (1). The process recalls Gennep’s theories of detachment previously outlined in Chapter 1. Here, Lambeth’s speaker ritually marks progress in physical growth mapping the stages from childhood to adolescence. Whereas Gennep argues that in the first stage of transition there is a withdrawal from behaviours signifying previous cultural conditions, Lambeth’s opening stanzas achieve a similar sense of estrangement (87). The reported dialogue of the parents is conveyed by italics rather than quotation marks; the formality
of “one” and “other” combines with the matter-of-fact tone to extend their non-gendered anonymity:

> Get the knife, one would say.
>
> And the other would extract
>
> the largest knife from the drawer. (4-6)

The speaker simultaneously emphasises the individuality of each parent and their separateness, as if the past events are filtered and the status of the parent-child relationship is ephemeral. The later use of “her” and “she” in the concluding stanzas emphasises a similar detachment of the adolescent figure from the adult speaker as they record the imperceptible change in psychical relationships between parent and child as the child grows into an adult (29-39).

In doing so, Lambeth re-appropriates Anzieu’s conception of how infants learn to distinguish themselves from others through a gradual, learned separation of identity from the parent which leads to the “re-emergence from the group” (33). She figuratively conveys the notion of the developing ego in the vertical “I” outline. The verse’s narrow structure is spatially uniform, conveying the elongated feature of a wall of words which are contained within the visual form of the “I.” The regular tercet format of each stanza alludes to the shadowy enjambed third “leg,” which signifies the dragging movement and hidden simultaneous presence and absence of MS. Enjambment between the extensive thirteen stanzas symbolises the outward progression, expansion and body growth, whilst the tight syllabic patterning forms a visual image of the interior discs of the poem’s spine. In contrast to the internal spinal gap displayed in “Seizure, or Seduction of Persephone,” Lambeth employs a tightly controlled, unbroken vertical nodular-like structure.

On this occasion, the positioning of the stanzas conveys the sense of an inverted structural skeleton: the white spatial gaps found between stanzas are indicative of the presence of white skeletal bones; the black text’s typographical presence is emblematic of something absent -
the black holes of each lesion. In other words, the stanzas are the holes; their presence inverts the norm of the white space void. Clinically, these black holes (hypointense lesions) are used to measure the progress of MS. They are the medical markers: “The formation and evolution of chronic or persistent T1-hypointense lesions (black holes) have been used as markers of axonal loss and neuronal destruction to measure disease activity” (M.A. Sahraian et al. 1). As such, the holes register “loss” which Lambeth exploits to highlight the paradoxical nature of medical definition and lived experience. She is able to contrast the relationships of parent-child with “the realization that my relationship with MS is the longest-running relationship in my life …” (“Old Friend”). Despite its intermittent nature, MS has remained a lifelong companion:

I learned that this did not mean saying good-bye to my friend; rather, it reminded me that even when MS wasn’t making his presence known, he was still around. Depending upon which medication, injections at regular intervals would remind me that MS was imperceptibly slipping his arm across my shoulders, particularly close to my spine. (“Old Friend”)

A sense of intimacy occurs when the “arm” encircling grip of MS is anthropomorphized as a gendered entity, signifying “friend” rather than “foe” (“Old Friend”).

Whilst “The Selection of a Child for Illness, A Fable” establishes a visual image of the poem’s tight external contour, one that outwardly appears to convey the concept of containment and control, when we analyse the internal structure and word placement of Lambeth’s verse there is an increasing sense of an instability. This contrast is emphasised through the altering perception of the speaker, the reconfiguring of the “I.” The poem’s speaker, for example, establishes an awareness of the disconnection between themselves and the expectations of previous audiences:

People are often alarmed
when I tell this story,
which is not a story, but

a ritual, the tool a knife, yes. (7-10)

Lambeth’s use of chiasmus alludes to the changes in expectations: from being a story, to being a story about a ritual, to the point where the retelling of the “story” becomes the ritual (8-9). The syntactical placement of “yes” as an affirmation of what has preceded it, adds to the momentum of the poem, emulating how the narrative is refined with each telling (10). The repeated references to a knife, however, emphasise that the poem is not telling a generic children’s fairy tale but one where real-life experiences cut through narrative conventions. As Scheuer observes, Lambeth models a “disability poetics that not only focuses on the subject of disability, but that also attends to how the poet's somatic and social contexts have impressed poetic form. Rather than merely telling a story about disability, a disability poetics restructures the way that stories of disability are told” (171). Lambeth highlights how we must shift our thinking, reshape the outline and plot a different kind of narrative.

This sense of detachment emphasises the sense of isolation that results from being marginalised by disability, especially when that disability occurs later in life. To emphasise the process of change, Lambeth disrupts the measured tightness of the poem’s internal structure. The tempo between breath and line lengths shift internally with the extended enjambment:

A new chart required for the life.

The wall dug its own scars – scleroses –

deep into her brain and spine,

but she, distracted by shapes

she found in knots of wood –

knife ticks mere shading on a bear,
eye, or bird – let it all in, unaware yet she could take it. (32-39)

The initial rigidity of its end-stopped lines begins to break down, signalled by the bracketed breaking off of the word “- scleroses -” (33) Subsequent dashes indicate an increasing fragmentation of syntactic parts which unsettle and interrupt connections. The container “cage” of the initial shape is now suggestive of expansion (“Reshaping the Outline” 175). The opening up of space to “let it all in,” models the enabling of new experiences which overturn the conceit of control (38). The tone is positive: whilst the child is ignorant of any internal bodily change, the perspective of the adult speaker encompasses the climactic “yet” emphasising assured change and future success (39). Importantly, the trope is not one of overcoming but of knowing.

A similar sentiment is expressed in Lambeth’s following observation:
… the urge to not sound like a narrative of overcoming is my primary reason for disrupting chronology. I take issue with narratives that begin with the originary moment of illness or disability and then go on until the person is either cured or dead. And in a way, the structure of Veil and Burn owes a lot to this disruption, too. (“Dialogue on Disability Poetry”)

The poem’s narrative is a story of hidden bodily disruption, a chronology replicated in the oscillating presence and absence of indentations on the wall; a transition is signalled by the need to open a “new chart,” a new map, a new surface, one that aligns and liberates disability and community (32). As Lambeth observes, “Poems need to be felt beyond the story of the poem and into the greater questions that arise like steam from the page” (“Dialogue on Disability Poetry”). Her poetry draws on the power of the lyric to enable readers to question and approach the world through different perspectives. Hall emphasises the “paradoxically liberating process of ‘formal containment’” and control in Lambeth’s use of traditional poetic forms (157). She notes Lambeth’s comments on how “fitting form to the poem, lending it shape and order, granted me a
tremendous sense of power” (“Reshaping the Outline” 176). My analysis indicates how Lambeth creates poems which “cage” and contain re-imagined experiences and simultaneously breaks free from the constraints of conventions and stereotypes:

What better opportunity to enclose and cage an illness that could, without the cage, spill its guts all over the page? The villanelle is an obsessive form with its repeated but slightly altered lines, and there's very little room to introduce new information, so the poet can reveal only so much, offer very few details, and they have to really count. I wrote about that night's seizure or moment of shaking. After that, I felt more comfortable expressing my physical experiences in various forms of free verse, knowing that the challenge is always to give voice to the inexpressible, while creating something beautiful about the body that can stand apart from the body. (“Dialogue on Disability Poetry”)

In marked contrast to the tightly constructed vertical structure found in “The Selection of a Child for Illness, A Fable,” the erasure poem, “EXAMINATION: MRI of the brain with and without contrast” is loosely framed and sparse in detail. We find the cage removed, the fragmented poem now deriving form and meaning from a process of erasure. Erasure is defined as a “found poetry” created by the rubbing out of words from a pre-existing text. Put simply, “the words on the page preceded the imposition of the given form over and around them” (Travis Macdonald). Words are erased and others are left in situ, standing suspended in white space, arranged visually to convey the unique MS experience of sensation and loss of sensation. Lambeth says that the technique enables her to reclaim language and alter perception:

Erasure is a process of uncovering and revealing (or sharpening) an alternate text, whereas my poems that move around off-margin are originally crafted that way to convey mood and pace. With regard to a medical test result or article, it’s satisfying to cross out and “correct” the original text’s dry misunderstanding of what it’s like to live in a body that doesn’t fit the norm. (Appendix 3 284-285)
The poem’s content and form originally derives from an external source - a confidential medical letter giving a clinical update on her prognosis. Language has been removed and surgically carved out whites spaces remain. This structure conveys the loss of a sense of self and the speaker’s experience of detachment even from her own body, represented through an explosion of seemingly disconnected words and space:

My Chart - Baylor Clinic - Test Details

Name: Laurie Lambeth

EXAMINATION: MRI of the brain with and without contrast.

FINDINGS:

Too numerous too confluent to count

unchanged since

deep

white matter left

black holes hypointense

unchanged.
volume loss,

loss within

abnormality. (lines 1-13)

The typographical representation of white gaps mirrors the fading away of bodily sensation. The inchoate form suggests the fissures which form the hypointense and hyperintense lesions in the central nervous system as MS progresses. Words synthesise into fragmented patterns of meaning signifying the divide between medical language and personal experience. In contrast to the often-static presence of the symptoms, the visual image is one of dynamic movement.

These spatial poetics capture the literal and metaphorical effacement of the body; they employ a mimetic process of erasure which places new emphasis on the language that remains. Whilst there is an initial visual cohesion, this seems to splinter; the poem appears to fracture into two parts until falling away into a single column of words. There is a balance created in the line, “too numerous too confluent to count” created by the repetition of too/to and the alliterative “c” (5). Similarly, the alternating contrast of “white matter” and “black holes” is mirrored by the inversion of “volume loss” and “loss within” and is suggestive of the balanced phrasing of remission and remittance (8-12). The word “abnormality” is a given prominence as a concluding statement that is psychologically destructive and damaging in its finality (13).

In this way, Lambeth draws attention to the richness and power of words that arise because of their new-found ambiguity. For example, the word “Findings,” is typically suggestive of something found, a presence discovered, but this meaning is countered by the repetition of “loss” which calls into question presence by presenting it as something nuanced and illusory (4-11). The rewriting of “loss” creates uncertainty: is it a negative or a positive finding? Does loss here signify gain - as in improvement in health? The treatment of the phrasing, “too numerous” and “too confluent,” appears ironic in this re-arranged context (5). The repetition of “unchanged”
similarly conveys the ambiguous nature of a state of being that has not worsened or improved (6-10). “EXAMINATION: MRI of the brain with and without contrast” triggers a wider consideration of language and its re-appropriation from the medical realm to the aesthetic; in this poem, the jargonistic language of the doctor’s formalised report becomes part of her own voice.

The treatment of the poem’s amorphous form recalls Anzieu’s description of what happens if the containing function of the skin ego fails. In such cases, the “wrapping does exist but without continuity, pitted with holes. This is the sieve Skin-ego: thoughts and memories are difficult to retain and they drain away . . .” (110). Lambeth uses a poetic framework “pitted” with spaces to represent the failure of the protective surface to maintain a continuous outline and to represent the cognitive gaps in memory. The approach leaves the poem’s skeleton frame exposed, “visible but opaque, redressed as it is in the flesh of what amounts to chance operation” (Macdonald). However, the selection of language, I argue, is not done by “chance” but carefully conceived and reclaimed. The spatial gaps resonate with meanings of their own; words are given new meanings or left ambiguous: stripped away from surrounding words, they appear to “float to the surface of the page” (Macdonald).

The nebulous format conveys a blurring of outline, a formlessness that represents an inability to hold the line and contain the space. As such, Lambeth’s work illustrates the type of dissipating outline that Thomas Ogden connects to forms of anxiety created by a lack of physical contact. Ogden argues that the failure to define the boundaries of the skin by surface to surface contact, which he terms “skin-to-skin ‘molding,’” leads to feelings of being uncontained: “leaking, dissolving, disappearing, or falling into a shapeless unbounded space” (68). For Lambeth, the physical experience of numbness on the skin means that disconnection between surfaces is inevitable. The numbing of feeling is symbolically represented through the poem’s displacement of words; this displacement is emblematic of the erasure of the disappearing self.

Lambeth’s conceptualisation of the unreliable, degenerative nature of MS as a process of
disconnection, fracture and erasure is represented through a mimetic relationship between her writing and the physiology of MS. In “EXAMINATION: MRI of the brain with and without contrast,” she explicitly connects this to her knowledge of Jacques Derrida’s development of Heidegger’s concept of “Sous rature” translated as “under erasure” (Of Grammatology 65). The use of a letter as her source material is reminiscent of Heidegger’s demonstration of the principle in a letter written to Ernst Junger in which he defines nihilism but finds the word “Being” lacks accuracy: “Since the word is inaccurate, it is crossed out. Since it is necessary, it is left legible” (Of Grammatology xxxii). In “EXAMINATION: MRI of the brain with and without contrast,” the erasure signifies both the constraints and the re-appropriation of language; where a word is inadequate, the original language in the found source is covered over with white space and a new synthesis of meaning results.

Lambeth’s spacing of words in “EXAMINATION: MRI of the brain with and without contrast” is emblematic of her cognitive disconnection: “I didn't know that my cognitive abilities would change, that following and synthesizing a number of strands of discussion would come less easily, or that remembering simple words would be much harder for me than for others my age” (Walton). In the rewriting, or rather rearranging of text, the power dynamic is inverted. Lambeth makes us question our assumptions. As she says elsewhere, it is a question of definition, asking “How do you define decline?” (“Decline”). Thus, for Lambeth, decline is an inadequate word to describe her condition; the changes in her body and her mind do not necessarily signify a problem if embraced as part of a natural process of living with a chronic illness. By re-configuring language, definitions can be re-appropriated and reclaimed. The three poems, “Enjambment,” “The Selection of a Child for Illness, A Fable” and “EXAMINATION: MRI of the brain with and without contrast,” all variously resist the language and definition of embodiment as a fixed entity and illustrate the figurative gulf between the outward appearance and its interior subjective reality. In this sense, she articulates how the invisible presence of some
disabilities are hidden, ignored, and separated from mainstream concerns.

**Section Two: Body Armouring: Shell Coverings and Second Skins**

As well as writing poems which graphically chronicle the unravelling of the body, Lambeth explores ways in which poetry can articulate a sense of physical containment, hardening and resistance. According to Claudia Benthien, “despite medicine's having penetrated the bodily surface and exposed the interior of the body as never before, skin, paradoxically, has become a more and more unyielding symbol” (1). Lambeth’s poems counter this inflexibility while paradoxically experimenting with imagery of hardening surfaces to explore semantic and psychic aspects of touching, feeling, and intellectual perception. The main poems, “A Trace for Jacques Derrida,” “Hypertonia” and “Symptoms,” discussed in this section are chosen because of the ways in which they depict how an individual’s physical contour can be reconfigured and reconstructed. Specifically, they document the poet’s progress towards a reclamation of disabled identity, a renewal achieved through the exploration of pain and affective emotion. On one hand, they express an alternative narrative, one with the potential to complicate and challenge stereotypical depictions and regain control of configuring body spaces. On another, they describe sensory and psychological defence mechanisms which function as metaphorical modes of protection against the physical pain and emotional fear of losing one’s sight, the ability to walk, and memory. What is more, they exemplify how Lambeth’s work creates an intimate yet celebratory discourse of embodied resistance, a “clear-eyed seeing of the worth of the material world” situated against the backdrop of everyday actions, intimate moments and mundane events (Northen “Book Review: Veil”).

My analysis in this section articulates in greater detail how Lambeth endeavours to counter conventional views of embodiment as a static, fixed outline, by re-imagining hardened
shell-like bodily boundaries and depicting them as encasing the speaker’s shifting interior consciousness. By re-appropriating the skin as a richly signifying surface, I argue that her poems explore how figuring the body as a hardened shell can be a mode of resistance, armouring the self against damaging expectations and the social invisibility often associated with MS. Indeed, the contracting body of the poem and the paradoxically expanding outlines of perception in Lambeth’s poems call to attention the complexity of experiences of MS. “Hypertonia,” “Symptoms,” “A Trace for Jacques Derrida,” “Retrobulbar” and “The Merle” all employ shell imagery to describe the outer surfaces of the body. These relate to Anzieu’s description of the skin as a “crustacean” envelope, a tough protective layer that encloses the soft internal tissues of the body. Anzieu’s *The Skin Ego* (1974) conceptualises the skin as a “substitute” shell (102). In contrast to Anzieu’s understanding of a single hardened outer layer, Lambeth’s poems represent multi-layered surfaces; her writing seeks to replicate the experience of numbness associated with MS through a focus on touch, on ambiguous physical edges, and multiple layers.

The poem “Washing Up” is useful here as an introduction to Lambeth’s approach to reshaping body contours; it presents an intimate yet celebratory discourse of resistance (*VB* 78-79). Situated in the domestic setting of the kitchen, the poem’s action is located in the space which Bachelard calls “the topography of our intimate being” (*Poetics of Space* xxxii). Lambeth voices a positive engagement in the ordinary “everyday” action of walking whilst bathetically detailing cognitive failings, physical and sensory impairment. The repetitive structural refrain of “Praise to” is iterated twelve times and echoes Ferris’s crip praising of abnormality in his verse “For Crippled Things”: “All things imperfect, asymmetric, strange” (*STG* 12 8). Ferris’s declarative line “Glory be to God for crippled things” is similar in tone to the speaker in Lambeth’s poem who utters hymn-like affirmations of agency and resilience (*STG* 12 1). Whereas Ferris’s speaker rejoices in the pleasure found in all bodies and in the parts of the body
that are in flux or outwardly different, the imagery in “Washing Up” focuses on the connections which bind body and mind together:

Praise to holding this invisible envelope — knowing it rests, a rein,

between my ring finger and my last. Praise to failing
memory's insistence that I always walked this way, forgetting

— was it last month? — that I shuffled, propelled the body with a cane;

and to the body's memory, noting what is to step when I am well. (VB78 2-6)

Lambeth’s trope of the “invisible envelope” chimes with conventional representations of the skin such as Anzieu’s notion of it as a two-dimensional interface that allows a “filter of exchanges” (10). Drawing on the earlier work of Sigmund Freud and others, Anzieu assigns three functions to the skin: firstly, as a containing, unifying “envelope” for the self; secondly, as a “protective shield and psychical container,” a protective barrier for the psyche (141); thirdly, as a “filter of exchanges” and a surface of inscription for the first traces, a function which makes representation possible (10). Anzieu specifies, “To these three functions, there correspond three representations: the sack, the screen and the sieve” (Dana Birksted-Breen and Sara Flanders 479). Whereas Anzieu’s discourse on skin has influenced cultural theorists interested in a wide range of issues such as body image, community relations, fashion, pregnancy, and racial identity, its application to discussion of disabled embodiment has been largely overlooked.

Lambeth’s poetry takes up this challenge, developing representations of body contours as the complex “surface . . . where the self meets what is other than self” (Drew Leder 11). Within this space of meeting points, the things that bind us together conversely allow freedom of movement and thought. “Washing Up” emphasises this in the phrasing: “Praise to holding this invisible envelope” (my italics). The interconnectedness between relational objects is extended
in the image of a horse’s “rein,” a leather strap used to guide, check, and control momentum. In another way, it is the tether that both situates and ties the speaker to others and what is “other than self” (Leder 11). The intermittent presence and absence of haptic sensation of MS experience is conveyed in these associative leaps between words, imagery and ideas. In this way, “Washing Up” illustrates how the skin is reconfigured as an interconnecting surface, a meeting point of societal practices, the place where “identity is formed and assigned” as Benthien notes, rather than a conventional “metaphor of separation” (17).

In an MS Connections blog post, Lambeth recounts how medical specialists ask about her cognitive lapses in memory. Communicating the number of these instances leaves her feeling exposed and vulnerable. She adds: “I wanted to shrink into myself. How strange it felt, as though a shell of silence had formed around me and nobody could come in or let me out” (“Is This Normal?”). The allusion to shrinking into a “shell of silence,” recalls Anzieu’s image of the psyche as an exposed shell kernel, one lacking adequate protection in times of anxiety (“Is This Normal?”). Anzieu states that the skin envelope exists to cover the internal organs but in times of anxiety is akin to a leaky “colander,” its continuity is “broken into by holes” (Breen 483). Failure of the containing function of the skin ego is like “a kernel without a shell; the individual seeks a substitute shell in physical pain or psychical anxiety: he wraps himself in suffering” (Breen 483). Anzieu represents the damaged skin ego as an organ that needs augmentation, a shell-like coating as a defensive shield.

The poem “A Trace for Jacques Derrida,” combines the notion of the coiled form of sushi with the concept of preserving the self. It explores the form of sushi and the way in which kelp is used as a kind of insulating skin for the fermented fish and rice. The speaker emphasises the underlying sense of security inherent in the sushi’s predictable regularity of construction as rice and seafood are bound together with a layer of kelp:

I was shrinking, so thin this felt right, warmed the gut
just enough. Comforting to know my food was small,
spiral of rice with bright colored centers, bound
tight by bands of kelp. I wanted to be that size,
put together that way. (lines 16-20)

Each groove of kelp folds round the preceding line in a parametric envelope of protection, preserving, containing and controlling the substance within. The alliterative “bands” encircle as defensive skins of “bone” (19). The sushi curls shell-like in its “tight” container of kelp, rolled and “bound” together, augmenting its outer layer to keep the rice from spilling and its formation falling apart (18-19). The structure of the seafood is replicated by the verse lines which are internally stopped, each caesura forming a tightly enveloping compartment.

Lambeth’s representation of sushi is of wrapped “spirals,” a geometric shape linked symbolically to rebirth, regeneration and creation. Spiral derives from the Latin spiralis or spira, and the Greek speira, translated as meaning a spire or coil, and the Latin spirare, meaning to breathe (Steven Schwartzman 204). The emblematic use of food as organic life-giving sustenance is combined, therefore, with breathing and sustaining new life. It also has symbolic associations of perfection inherent in the mathematical formulae of the Archimedean spiral, an expanding spiralled geometry as discussed by Descartes in 1638 (Simon Bell 22). The nautilus mollusc’s logarithmic chambers follow the “Fibonacci” sequence, with the previous two numbers being added together sequentially (1,1,2,3,5,8). The key element of the shape is its consistent linear trajectory and constant speed of movement through space on a fixed axis. Lambeth contrasts this with the radical unpredictability of MS experience. The mollusc’s body is constructed and understood as expanding outwards with geometric precision whilst, paradoxically, the speaker in the poem experiences heightened self-awareness which causes her body to enfold and shrink inwardly. In contrast to the sushi spiralling outward on an ever increasing radius, they shrink inwards, reducing until reaching the final destination in the single
word sentence “Ash?” (24). The word choice alludes to the journey that everyone takes towards is death yet the notion of spatial shrinkage is also unexpectedly empowering, an experience that “felt right,” something desired and controlled:

Do you think even sushi could be dismantled before being eaten? Literally?

When would it cease to be sushi? Could the body, bone blades hanging the flesh, be separated, sorted, categorized before the autopsy, the ossuary? Ash?

If only, I thought, I could be that small without

Dismantling, to fade to a slip of a girl, a trace. (20-26)

Lambeth juxtaposes the image of the body’s “small” circumference with remaining mentally expansive, protected yet filled with an interior of aesthetic perfection (25). Speculation on the type of shell that might be formed, the “spiral nautilus” or “hinged mussel,” juxtaposes the aesthetic perfection of the nautilus shell with the enveloping frame of an invertebrate cephalopod (8).

The direct address to the reader expands the poem’s argument with a series of rhetorical questions which invite further speculation on the metaphysical limits of subject-object bodily boundaries. Merleau-Ponty’s thinking blurs the separateness of the body contour from its environment, context and experience. He asks whether the body as a “visual thing is contained within the full spectacle” since experience of the world is determined by the information gained through the senses (136). For Lambeth, however, the issue is a consideration of what changes when the senses such as touch and sight no longer function. The series of rhetorical questions in “A Trace for Jacques Derrida” challenges, extends and radically reconfigures visual perceptions
of the self through the sense of coiled layers and interior sensations. Lambeth and Merleau-Ponty are questioning if our existence is only determined by “wholeness” or if we can live and remain complete if parts of our being is eroded. Lambeth’s speaker contemplates whether she could rescue her body and “be that small,” the size of sushi and still be visible to the naked eye (25). Merleau-Ponty similarly expresses a desire to know if “full spectacle” is necessary for our being or if parts of us can remain hidden without us vanishing (136).

To inhabit disability consciousness, Lambeth comments, is to be open to expressions of “multiple possible originary moments” starting points not only of MS symptoms but of multiple ontologies (“From Metaphor to Metamorphosis”). The notion is echoed in Ferris’s poem “Facts of Life” when the speaker states that the “meat, substance” of his flesh is not his “essence” but a meeting point which opens up to possibilities and expands into a wealth of different interpretations of the world and the self in a “cosmos of possible ontologies” (FL13). Whereas Ferris’s concern is with the nature of being, the subject matter and title of “A Trace for Jacques Derrida” directly references Derrida’s conceptualisation of the origins of words and meaning through language. Derrida extends the notion of sous rature to demonstrate that meaning is to be derived from difference rather than by its reference to pre-existing ideas. He sums up the notion of the trace:

The trace is not only the disappearance of origin — within the discourse that we sustain and according to the path that we follow it means that the origin did not even disappear, that it was never constituted except reciprocally by a non-origin, the trace, which thus becomes the origin of the origin (Of Grammatology 61).

Derrida’s concept of “trace” as the sign left by the absence of the original is significant for Lambeth’s poetry because of the sense of the trace as the absent part of the thing’s continued presence. Lambeth shifts the concept of the trace, transferring it from the origin of language as signifier to become a way of understanding and narrating her own bodily existence. Her poems
are often structured in ways that visually represent spatial gaps signifying both the “disappearance” of MS symptoms when in remission and the “disappearance” of touch sensation when flare ups occur (Derrida 61). Elsewhere, Derrida argues that discovering the “trace” origins of words is an impossible quest, a “disappearance” of language and knowing which is analogous to an “erasure of selfhood”:

The trace is the erasure of selfhood, of one’s own presence, and is constituted by the threat or anguish of its irremediable disappearance, of the disappearance of its disappearance. An unerasable trace is not a trace, it is a full presence, an immobile and uncorruptible substance. (Writing and Difference 230)

Poetry enables Lambeth to negotiate observations mediated from inside the inhabited “presence” of words which struggle to define lived experience (Writing and Difference 230). Lambeth resists language that simplifies MS experience and fails to acknowledge its presence. It is not possible, she argues, to “embrace the certainty of a single generative moment” of her complex condition (“From Metaphor to Metamorphosis”). Instead, she experiments with ways in which language offers new possibilities generated from the arbitrary disconnection or juxtaposition of disparate objects, words and ideas. Exploring the relationship between language and thought, she interrogates different ways of representing physical experience and the boundaries of the body as an “unerasable” experience (Writing and Difference 230). Metaphors of shrinking and hardening contours represent this defence against the erasure of experience through situating the body as a contracting space.

“Hypertonia,” for example, conveys the metaphorical hardening of the body into a clam-like shape; this suggests an attempt to regain control over the boundaries of her bodies and the definition of her condition. The violent tightening and spasming of muscles is conveyed in visually rippling line lengths. Like muscles that cannot be controlled, words shake free and fall like food from a fork:
Without intent, the muscles

contract, spasm, tremor,

kink, shut the jaw, shake

food loose from the fork,

stun inert limbs awake.

Once, I was nearly shut entirely,

uncertain what shape I might take,

spiral nautilus or hinged mussel.

Is the shape of life a great tightening,

spun into ball or pressed into board? (lines 1-10)

The simple act of eating food becomes a challenge, a reminder of fragility and frailty. The alliterative “food” and “fork” provide a momentary staccato rhythm before the next “tremor” takes precedence, disrupting the momentarily controlled, repetitive movements in the act of eating (4). The repeated action of hand connecting with mouth is interrupted by the cumulative list of sibilant bodily reactions which “spasm,” “shake” and “shut” and build towards the speaker's climactic rhetorical question (2-3). According to Mikhail Bakhtin, eating is the most significant interaction between self and the world; he states: “Man’s encounter with the world in the act of eating is joyful, triumphant; he triumphs over the world, devours it without being devoured himself. The limits between man and the world are erased, to man’s advantage” (281). Through eating, the “confines between the body and the world are overstepped by the body” as a triumphant moment of overcoming (282). However, in “Hypertonia,” the concluding lines focus on the abstract notion of the “shape of life” to come, representing the future as an uncertain contour that is more about becoming rather than “triumphant” overcoming (9).
In “Hypertonia,” Lambeth’s speaker presents the body as being of yet “uncertain” shape while dormant chromosomes and neurons lie “inert” (5-7). The stanza’s enjamed lines alternate and extend spatially, mirroring the contraction of surfaces which appear to narrow and separate, therefore creating a visually undulating spine which runs throughout the poem. This visual shape is reminiscent of a strand of DNA and emblematic of the genetic framework of life. Indeed, the poem’s graphic shape is a representation of an enfolding organism undergoing a process of symmetrical morphology. The image resembles the formation of a Möebius strip, a surface that according to Stephen Connor “both exceeds and includes itself” (23). Connor’s description evokes an image of an enfolding infinity which Lambeth projects on the page. Marc Lafrance also highlights the complex reversibility of the Moebius surface: “A topological construct, the Möebius strip can be described as a three-dimensional figure eight or, put differently, a flat ribbon twisted once and attached end-to-end to form a twisted surface” (17). The notion of a twisting contour is represented by the vertical structure of “Hypertonia,” its black typography zig-zags through the controlled spacing of syntactical metre. However, the poem’s content negates the associated flat ribbon surface and instead presents a figuratively enfolding one. As Grosz explains, “The Möebius Strip has the advantage of showing the inflection of mind into body and body into mind, the ways in which, through a kind of twisting or inversion, one side becomes another” (xii). It is this aspect of the image that appears reconfigured in Lambeth’s poetry, representing a complex re-imagining of embodiment as an inversion of surfaces. Where Lambeth extends this analogy of the moebius image is in her rejection of the contour as a single surface; instead she replaces it with dual surfaces.

In “Hypertonia” the language is of potentiality, expressed in the phrase “what shape I might take” (7). The speaker communicates this uncertainty, documenting feelings of mounting trepidation about the unreliability of her body and memory. Each line creates a sense of momentum and tension which Lambeth asserts is “akin to the ways enjambment can offer
counter - movement or intensification within a poem” (“From Metaphor to Metamorphosis”). The counter flow of the spasming wave-like verse is underlined by the regularity of the controlled syntactical length of each line and the tight rhyme of the “k” consonant in “shake,” “awake” and “take” (3-7). The intensification of the monosyllabic repetitious listing of “shut” and “shape” are juxtaposed with the relaxing of drawn out vowels in “loose” (4). The word choice of “spiral” reconnects with the sushi imagery in “A Trace for Jacques Derrida,” forming a thematically interconnecting thread of imagery and language. In “Hypertonia,” however, the continuously augmenting structural beauty of the nautilus spiral is juxtaposed with the symmetrical bivalve hinged shell formation.

The poem depicts a scene in which the speaker’s knees tighten inwards towards the chest, enfolding, building layers of protection. The resulting hinged shape is replicated in Lambeth’s article “From Metaphor to Metamorphosis” (2016) which details memories of the event in prose. The graphic rather than textual representation offers an alternative dialogue through which to explore the same image of the body as a hardening, enclosing shell. “Hypertonia” recounts the experience of taking new medication at “full-strength” for the first time (“From Metaphor to Metamorphosis”). Lambeth describes how she felt as if she was clamping shut: “I was a literal shell clamping shut, less metaphor than metamorphoses”; she recalls how “as my muscles clamped shut bit by bit, I felt like I was becoming a shell,” the body overlapping and encroaching on itself (“From Metaphor to Metamorphosis”). The hinged vertebrate image plays on the association of mussel shells and tightening muscle:
The image of the “shell” body “hardening up” chimes with/connects to Frances Tustin’s sense of the body as a “crustacean” envelope which blocks outside stimulus in sensory-sensitive autistic children, eliminating the unknown and the unpredictable (50). Though they deal with very different conditions, MS and Autism, both Tustin and Lambeth use shell-related imagery to express experiences of alienation and the way in which language can act as a barrier. Tustin outlines how a crustacean-type shell forms if the functions of the Skin-Ego are not acquired: a rigid shell “encapsulation” replaces the missing container, preventing those functions of the Skin-Ego from being “triggered” (117). She describes autistic people as “child-shells” or “crustaceans” taking refuge, projecting a protective shell-like barrier against social interactions (Tustin 113). In a similar way, Lafrance sums up how somatic armouring can be viewed as a
type of “muscular or intellectual carapace — one that offers containment while it denies the need for an external object” (20). Lafrance’s term “carapace” directs us to a comparison of the muscular skin and/or imagination used as a protective exoskeleton shell, a chitinous case or shield, similar to the hard-outer defensive covering of a crab or snail (10).

Lambeth’s re-imagined experience of the body as a shrinking, contracting contour also connects to psychological methods of self-preservation that Wilhelm Reich describes in *Character Analysis* (1933). Reich introduces the concept of character “armouring” in a study of how individuals regulate sexual energy. He indicates that the process of armouring functions most commonly when “The character armour is formed as a chronic result of the clash between instinctual demands and an outer world which frustrates those demands . . . It is around the ego that armouring is formed” (156). Lambeth’s sensual poems can be read through the lens of Reich’s body “armour” concept. In the latter stages of “Hypertonia,” the speaker emphasises how the sexual energy from sensual touch and intimacy breaks through the “weight” of “this life” (16). The word choice “spell” suggests the magical nature of existence whilst enfolded in the arms of a lover/partner:

> It must carry weight, this life,
> all accumulation and heft,
> into the taut
> whisper of motion for a spell.

> When you hold me, living,
> the muscles yield to you,
> but never entirely release.

> When I am lifted to that final
place, they will slacken,  
the body a relaxed, melting thing.

And again tighten. (16-26)

The body is presented here as a flexible container of contradictions possessing the need simultaneously to reduce its size and continue to expand. Described in the third person as “It,” the body is sustained by its ability simultaneously to hold “taut” and yet “yield,” unfurled by a lover’s touch (18-21). The wavering triad formation and cumulative enjambed lines mimic breathing and the tightening and slackening motion of contracting and relaxing muscles. In the poem’s final section, the rhythm of “this life” continues in a motion of contraction and release (16). When death claims the body, each limb will momentarily melt and “slacken,” letting go as breath leaves the body before rigor mortis causes muscles to “again tighten” and stiffen (24-26).

Whilst the shell image in “Hypertonia” depicts a somatosensory response to ingested medication, the psychological response to the symptoms of MS is also explored. It is presented as one which limits bodily relationships to the concrete and the visual. In a subsequent blog entry Lambeth remarks: “My body experienced hypertonia and all the muscles tightening, tightening so I couldn't work my tongue. I could not work my jaw. I could not ask for help when I needed it . . . I felt like a shell. I felt my body was hardening up. My body was clamping shut. My knees were coming up to my chest. My arms were tightening” (“Avoiding Cliche and Over Sentimentality”). The admission that she could not “work my tongue” or break through the tightening barrier to ask for external “help” is indicative of how she considers herself narrating from inside the shell-like exterior (“Avoiding Cliche and Over Sentimentality”). She regains her voice through writing and narrating the experience of speechlessness and also seeks to give others access to this agency in the spaces of her poetry.
Lambeth also depicts various tightly-bound bodily contours from which the mind and voice break free. The speaker in the poem “Symptoms” acknowledges the difficulty of appropriating language to articulate intermittent haptic sensation: “I’ll try to tell you how it feels” (VB3 1). In “Symptoms” the analogies of bindings refer to coverings such as clothing and fabrics which guide, reshape, and support. The body’s frame is reinforced, stiffened and reconstructed by the addition of the old fashioned undergarments:

I’ll try to tell you how it feels: girdle

my grandmother wore, tight-laced corset
worn by her mother in Wales, but it seldom
slips from my ribcage. No hooks or laces, only

spaces of remission, then relapse,
a trip to the ancient clothes again:

crinolines, skirts grazing ankles, long
satin embroidered sleeves that rub and pull

naked skin, saying, now and then you must
try to feel through this, and this. All that fabric
wound around torso, legs, the dresses
and sheets binding to keep me in (VB3 1-12)

The compact layout mirrors the process of containment as each quatrain is presented as a visually rigid perpendicular column. The metre remains uniform rather than a wavering or dissipating formation. Noticeably, the clothing items referenced conceal, confine and restrict movement as well as impede the wearer’s ability to breathe or expand with food intake. The
whale-bone stays which constrict the body suggest the sensation of contours shrinking and stabilising. The “girdle” and “corset” are highly symbolic: they reshape and control (VB3 1-2). If, as Judith Butler argues, the “‘body’ is itself a construction, as are the myriad ‘bodies’ that constitute the domain of gendered subjects,” then Lambeth’s construction appears to move fluidly through this generational history of different conceptions of gender and fashion (Gender Trouble 12).

The speaker equates the constricting garments with the numbing of sensation in the lines “you must | try to feel through this, and this” (VB3 9-10). According to Scheuer, the repetition of “this” emphasises the “multidirectionality of feeling, which functions as both transitive and intransitive, connecting the body with the outside world and to its own interiority” (156). Unlike the corset garment, MS symptoms encasing the body are not so easily removed: the sibilant “seldom slips” emphasises their permanent presence; there are no “hooks or laces” to ease pressure from the grip of spasticity or the liminal “spaces of remission” (VB3 3-5). The gaps between symptoms are equated with being exposed and “naked” then confined in “fabric” coverings that “bind” (VB3 12).

This imagery in “Symptoms” evokes Anne Hollander’s assertion that clothes are the ghosts of fashions past: “All nudes in art since modern fashion began are wearing the ghosts of absent clothes —sometimes highly visible ghosts” (86-87). These “ghosts” compare to MS symptoms, the “sheets” which wrap around like shrouds as reminders of mortality. David Kunzle notes how the corset specifically is an item of clothing associated with “reshaping reality in the reality,” and corresponds to a “historical nexus of social competition, sexual repression, sex-role redefinition, and even economic and political anxieties, rather than some a priori aesthetic preference” (96). Lambeth explores this history of clothing and corseted selves through the cumulative lists of garments passed from grandmother to mother and daughter recorded in her poetry. In this way, she crips the notion of reconstructing the body to match aesthetic ideals and
highlights the superficiality of such societal values. Goffman emphasises how clothes signify cultural customs and values; these signs operate as institutionalised non-verbal communications within particular cultural contexts. Dress operates as a visual presentation of the self, communicated through dress code, a vocabulary of body symbols: a common “body idiom” (“Stigma and Social Identity” 35). In “Symptoms” Lambeth signifies how clothes cover and paradoxically expose the internal self:

    bed. The cure is rest, they tell me. Dizzy,
    drunk when I haven’t drunk, I’m drawn
to the wall to prop me. I’ve been known to sport
    a cane, per the fashion, to smooth the gait. (VB3 13-16)

The “fashion” here is the accessory of the “cane” as a walking aid to “smooth the gait” (VB3 16). The image is associated with medical notions of refashioning bodily form through the word “cure” (VB3 13). When Kuusisto refers to his white cane by asking the question “Without the cane, who will understand me?” he draws attention to the stigma and fear of being dismissed as disabled (P67). He implies that his visual impairment remains hidden until it is revealed by the signifying sign of the cane. For Lambeth, the appendage signifies the superficiality of cultural trends which “smooth” and mask underlying attitudes to disabled embodiment (VB3 16).

In the concluding stanzas of “Symptoms,” Lambeth articulates how poetry helps refashion stereotypical attitudes even when the “muscles” of the “mouth” and “speech” are “tired and stiff” from lack of use:

    Fix my mouth in a loose pout when speech
    eludes its muscles, tired, stiff as the garments
    that hold me. On occasion, they’ll fall
to reveal this body, a window of cellophane
wrapping my limbs, a ring for each finger. (VB3 17-21)

The word choice “reveal” elucidates how the notion of uncovering and exposing the reality of embodiment is made possible through the written word (VB3 20). The muscles loosen like unfastened “garments” and “fall” to expose reality (VB3 18-19). Revealing the interior self is made possible through imagery which depicts covering and uncovering as exposure of the embodied self. The “window of cellophane” introduces the idea of a voyeuristic opportunity, a brief moment through which readers might glimpse reality (VB3 20). The word “cellophane” links to the transparent film surface of the gauze screen and binds the poems thematically by the allusion to film reel cellophane (VB3 20). The transparent envelope is fashioned around each “finger” like a marriage “ring” binding lovers together, but the covering is also a barrier, one that reveals, protects and shields against external threats (VB3 21).

Lambeth’s writing depicts her concern for her decreasing capacity to recall words, to speak or remember. For Lambeth, these black holes in memory occur unpredictably as cognitive ability falters; fear of future impairment fills the space of the ego’s capacity to think and brings with it a growing awareness of mortality. Thoughts fail to synthesize and remain separate “strands” like disconnected threads, emblematic of fragmented feelings and insecurities brought about by not knowing what the future holds:

I thought that if I could no longer count on my body, I could at least rely on my mind. I didn't know that my cognitive abilities would change, that following and synthesizing a number of strands of discussion would come less easily, or that remembering simple words would be much harder for me than for others my age (Walton). Lambeth constructs contours of hardening coverings, therefore, to represent the need to cover and uncover, to contain and unravel interior and external structures of defence. She exposes subjective and highly individual physical experiences through a recurring set of metaphors to do with removing protective layers of clothing and fabric bindings which constrain as well as
support. In this way, she seeks alternative ways of representing and imagining the complexity of MS embodiment through her writing.

**Section Three: Uncovering and Exposure of the Body**

This final section expands on Lambeth’s conception of the body as a layered site of contact and exchange in verse that “maps the body’s interchange with the external world” (Black). It investigates representations of experience as transference not only across and between surfaces but as the exposure of inside and outside edges, through and within the body. The selected poems, “Dysaesthesia,” “Hypoesthesia,” and “Coming Down,” express a complex understanding of bodies as mutually transformed by co-constitutive relationships but they also foreground the way in which touch is central to these processes. John Dewey states that “all behavings” are “transactional” and “co-operative” in the processes of “knowing” but Lambeth wants to communicate what happens when bodies are unco-operative (vi). For Lambeth, the concept of the skin as a symbolic field, a contour between self and others, is further complicated by the fact that numbness is a common symptom of MS. For Davidson, “The skin is a boundary. It is also a means of identification and recognition; appearance is one source of our difference from others and marks out age, gender, social status and nationality” (*Ideas of Space* 99). In “Dysaesthesia,” “Hypoesthesia,” and “Coming Down,” Lambeth indicates how the relationship between the skin and external others becomes more ambiguous when the sense modality of touch is unreliable.

Since touching as physical contact “always takes place at a limit” and “involves a gap; it goes across distance” and between surfaces, “being touched” by contrast implies an intimacy of connection between tactile and affective relations that implies *depth* (41). Edith Wyschogrog observes that “to be touched” is to be moved in the whole of one’s being (199). According to Scheuer, there is an “enigmatic relationship between the particularity of somatic “feelings”—the
body’s experience of itself and the spaces and objects with which it interacts — and emotional expression” (155). This tension “between the limits and possibilities of communication in speaking about emotion and illness” is highly prominent in Lambeth’s writing (158). Her poems close the literal and figurative distance between reader and writer to communicate the inherent vulnerability of bodies that are ignored; she represents bodies whose socio-political presence is not felt; and bodies that are marginalised, left situated at the edges. As Mark Doty observes “Laurie Clements Lambeth understands that the crisis facing the speaker . . . is an intensification of what it is to be any body, the edge-of-crisis on which we all dwell” (“Blurb”). Figured as responses to touch, these “edge-of-crisis” encounters are made more complex and informed by the way the numbing of sensations associated with symptoms of MS make distinguishing between surfaces problematic. For Lambeth, the intensification of emotional, psychological and physical pain is conveyed by associative links and blurring of veiled edges in poems which resonate with the “complex mixture of numbing and sensation” that make it “difficult to distinguish her own body from the objects outside of it” (Scheuer 156). Lambeth’s writing responds to the challenge to make this numbing of corporeal contours more visible.

“Dysaesthesia” explores the disconnection caused by the inability to sense different textures through touch. It uses a concrete visualisation of its structural form to suggest the notion of body contours touching and yet, paradoxically, remaining spatially and emotionally separate. The medical term for the condition comes from the Greek word “dys,” meaning “not-normal,” and “aesthesis,” which means “sensation,” to convey numbness or wrong feeling as “abnormal sensation” (O’Toole 574). Lewis Rowland defines the symptoms as “disagreeably abnormal sensations evoked when an area of abnormal sensation is touched” (24). Lambeth re-appropriates the term in order to procure a more accurate poetic representation of MS embodiment through aural, visual, olfactory, oral, haptic and tactile somatic sensations. The altered sensation, Ann
Pietrangelo observes, is pain triggered in the extremities “such as burning, electric shock, or a general tightening around the body, also called the MS hug” (“Dysesthesia”).

In contrast to the close connectivity suggested by the image of Pietrangelo’s “MS hug,” the poem “Dysaesthesia” splits into two; it displays the invisible interior spine of uneven syntax with lines asymmetrically broken as if being hung on an invisible hinge:

When I tell Ian       my hands are on fire,
when I first pull   them from the warm bed
and release them    to the air’s sting,
begin the morning   routine, measure
dog food, twist open ridged lids of jars
upon which I scratch my palms,
when I lift and unscrew the milk bottle,
fingers sparking without cause,
when I pour coffee, rubbing the hands
on any rough surface because they smolder, (BV182 1-10)

The verse form represents the body contour broken apart and displaced into two columns. Verbs like “scratching” and “unscrew” are separated from their relational objects of “milk bottles” and “jars”; this conveys a sense of disconnect between act and intention (BV182 5-7). It also suggests a potential split between internal and external surfaces which fail to connect. Instead, they coincide, coexisting yet remaining as separate dualities; these can be read as indicative of the neurological lesions that give rise to pain in outer extremities among people who have MS. The effect expresses the duality of numbness and pain, the dichotomy of sensation felt and not felt, experienced at a level of the skin’s surface:

Not hot, just on fire. Flameless, sourceless—
how else to say it but fire, this mistake
creeping between spine and skin? How to discern this pain, these hands, who operates them? (BV182 26-29)

Lambeth’s image of the “hands” suggests that they are ineffective, unable to grasp and open the containers (BV182 29). Feeling is a “Flameless” fire, its “sourceless” pain the low intensity of a “spark” (BV182 23-26). This contrasts with the “fire” of MS symptoms which grip and “hug” in alternative ways (BV182 26). The phenomenon of invisible pain leaves the speaker unable to “discern” through touch. The distance between surfaces is perceived as distinct, without synthesis or fusion. The poem’s climactic rhetorical question “who operates them?” evokes a Foucauldian concept of embodiment subject to external control by “invisible colonists” and oppressive powers (BV182 29). The question asks readers to consider what happens when haptic connection is missing: who or what controls the reins?

This de-familiarisation of conventional representations of touch is also central to Lambeth’s poem, “Hypoesthesia.” The title is the medical term for partial or total loss of sensitivity to sensory stimuli. It opens with the factual inscription: “Hypoesthesia: numbness, the absence of sensation. Absence often feels like something” (VB44). The phrasing confirms how the absence of sensation is projected as a type of “something,” an undisclosed marker of deferred presence. Furthermore, the italicized epigraph revisits the theme of altering contours in its implicit reference to the expanding number of sites of numbed sensation. Paul Schilder notes that bodies “can shrink or expand; it can give parts to the outside world and can take other parts into itself” (202). Whereas Schilder’s comments point to an external process, “Hypoesthesia” emphasises the absence of intimate physical connections between two lovers. The theme is made apparent by the epigraph which references Doty’s relationship with his partner Wally, who died of AIDS. It cites lines from his elegiac poem “Atlantis”: “All those years/ I made love to a man without thinking/ how little his body had to do with me” (Scheuer 170)

“Hypoesthesia” is significant, therefore, for the way it explores how these intimate
physical experiences might be shifted when touch as a sense is not present. It relates the sense of numbness and disconnection during sexual encounters. The poem pivots on the epiphany that she can experience her lover’s desire by using alternative senses to touch: watching and listening. Situated as an exposed being, lying naked and vulnerable, the speaker notes the irony of the moment that gives clarity, as one heightening awareness of separateness and lack of feeling:

For now (who knows how long now is) his touch is nothing but warmth
and trace
trailing his hand up my thigh and around my stomach. I feel a little
something crystallize after each pass of his hand, then it’s dust.

Whoever thought sex could be so literally senseless? (VB44 1-5)

The shadowy sensations of touch are likened to fragile elements that are momentarily present, “crystalise,” harden and take shape but then break apart (VB44 5). The physical touch is unable to discern the tangible from the intangible. The connection is felt as a “trace” of experience in the form of a residual warmth, a barely discernible memory imprinted at the point of contact (VB44 3). The physical connection is incomplete, the detachment signified by the distance between the opening stanza and the suspended rhetorical question. For Mika Elo, touch, “coming into touch, or being in touch . . . involves an exposure,” as experientially, it is an opening up to what is foreign to it, something outside of itself (49). In “Hypoesthesia” physical proximity exposes the vulnerability of embodied existence in a body that is “senseless” in order to question what makes a body viable (VB44 5).

“Hypoesthesia” also connects back to imagery of shells and hardened outlines through Lambeth’s image of the “carapace”:

I wanted to cry this time, too, another first since the new flare-up broke:

feet, knee, thigh, stomach, hip, hollow of the back, neither my body nor
my skin
but a loose-fitting carapace, bubble, prosthetic even.

*Are you touching me,*

I thought to ask, but instead watched as he kissed each part and caressed
and did what we do when I feel right. I didn’t say *I can’t feel that,*
but let his hands and mouth travel. (*VB44* 10-17)
The cumulative list of separate body parts conveys the wide reach of the medical condition
which “broke” out as a “flare-up” and “broke” through the “loose-fitting” boundary of the body-
shell container (*VB44* 10). The italicised dialogue “*Are you touching me*” omits the rhetorical
question mark, undermining the certainty of conscious somatic perception. Instead, the speaker is
guided by intuition and memory of previous success (*VB44* 14). The poem repeatedly alludes to
hands touching surfaces without the ability to discern between different sources of sensation. The
overlaying of body surfaces actually heightens the sense of failure to intertwine emphasising
distance, alterity and exteriority.

These references to hands that caress but “*can’t feel*” challenge the privileging of touch in
some theories of the senses (*VB44* 16). For example, Lambeth’s experience of hypoesthesia
which leaves the body sense-less counters Merleau-Ponty’s discourse which focuses on touch to
explicate the relationship between the touching subject and the tangible touched object. He
explains this as occurring when “my hand, while it is felt from within, is also accessible from
without . . . Through this crisscrossing within it of the touching and the tangible, its own
movements incorporate themselves into the universe they interrogate” (133). He argues that
every touch of the object is “simultaneously an auto-affection” which means the object is
simultaneously touching back, touching in the act of touching (Claus Halberg 110). As a
consequence, the roles of touching are exhibited as reversible, with each converting or
metamorphosing into its other. Whereas Merleau-Ponty emphasises the reversibility of touch as a point of connection, Lambeth explores the way in which touch can act as a one-way experience and in fact exacerbate feelings of isolation. In her writing this does not remain static: the speaker’s experience fluctuates between charting the presence and the absence of haptic sensation; the body is exposed in this depiction of a most intimate and private moment.

This notion of exposure, of naked truths being revealed, is also explored in the dialogic poem, “Coming Down” (VB1). A central theme of “Coming Down” is the uncovering and opening up of external body surfaces through a lover’s touch in deeply private moments of sexual intimacy. Lefebvre outlines how sensations and desire can help release the body from inertia turning the body into a site of resistance: “Thanks to its sensory organs . . . the body tends to behave as a differential field. It behaves, in other words, as a total body, breaking out of the temporal and spatial shell” (Lefebvre 384). The “sensory-sensual” body produces difference through biological, psychological and social rhythms, gestures and imagination to distinguish the ways in which the body is intimately connected to the world (Lefebvre 211). This outlook, however, is viable if an individual has complete sensory perception.

“Coming Down” articulates the irony of a body deemed deficient in haptic sensitivity and yet is highly attuned to different societal and cultural spaces and relationships. On this occasion, Lambeth uses the gendered symbol of a wedding dress to challenge constructed normative assumptions about embodiment aesthetics and expose the superficiality of social practices. This is represented by the process of counting down time, deconstructing the space and object in the unbuttoning of the dress. The removal of the fabric is representative of the removal of external societal values and systems which attempt to define and control. The silk cloth is a metaphorical “second skin” signifying the newly adopted role of married life. The event is watched by the speaker’s partner in a moment that is usually associated with new beginnings. The stripping away of clothes is structured by the numerical framework of the 19 “nub buttons”
which line the spine (VB1 2). The 16 couplets mirror the speaker’s vertebrae; the dress’s “corset” of bones creates a parallel structure of joints; one set of supports is natural and the other fashioned and synthetic:

Starting from the top, my husband undoes nineteen nub buttons lining my spine.

Three open. *Where exactly is the flaw that brought down the price?* He’s searching for tears in stitching.

Plucking the side of the skirt, I show him:

faint streaks of yellow flowing from the bodice,

seeping dark into the skirt’s organza folds,

each widening down to wash. Six. *A kiss.* (VB1 1-8)

The speaker refuses to cover up what might conventionally be perceived as imperfections in her body or her dress. The dress is purchased at a bargain price, the “faint streaks of yellow” refer to the discoloration of fabric yellowed by sunlight and marked by the natural passage of time (VB1 6). The rhetorical question “*Where exactly is the flaw . . .?*” is a veiled comment not only on the dress, but also on the flaws in societal values and narrow definitions of aesthetic beauty (VB1 3):

An hour of worry at I Do, I Do, for naught.

*All white yellows over time,* I say.

Nine: I can feel half my back undone.

*This dress just aged a little faster, oxidized*
The speaker reveals how the blemishes of the dress’s discoloured fabric correspond to the flaws on her skin. Oxidation has “burned” the dress fabric; this in turn evokes the burning symptoms of MS. For example, Dysesthesia and Paraesthesia are types of MS symptoms which include intense altered sensations, burning pain from pins and needles, tingling, and areas of skin with heightened sensitivity to touch. Fantasies of the dream wedding day are caught up in false notions of perfection and superficial worries that, for the speaker, come to “naught” (VB1 9). In her critical writing, Lambeth emphasises the significance of choosing the wedding dress as a metaphor for the body:

Metaphor is more than just a simple comparison - body equals dress; body equals shell. It goes beyond symbol. It goes into imagery whilst still kind of hovering in the land of the metaphor and shimmering between the dress being a metaphor for the body the body being a metaphor for the dress. Back and forth; back and forth. I like the way they mash together (“Avoiding Cliche and Over Sentimentality”).

The transactional “back and forth” process moving between concrete and abstract concepts is transformative, de-familiarising the trope of fixed embodiment, blurring the boundaries in order to “subvert reality” and complicate conventional ideas (“Avoiding Cliche and Over Sentimentality”). Whereas Ahmed and Jackie Stacey label the skin as a “boundary-object that allows the contours of the body to appear as a given,” in “Coming Down” Lambeth endeavours to convey the liberation felt in the casting off of the repressive presence of cultural conventions and the clothing as a second skin (2). There is a distinctly spatial element to Lambeth’s conception of “mashing” together words and “hovering” between states of being, peeling away the layers of the body to expose the universality and fate of all bodies. Uncovering the body signifies the exposure of reality versus the illusion of stable bodies biomedically cured, socially constructed and interpreted in society:
Nineteen. He opens me, guides the straps
down my arms. All that fabric purling
at my legs, foam and waves taller than my knee—
for a moment I feel the birth of Venus. Then
I see my body: bulges smoothed by corset, spine
stippled with lesions, glowing red injection
lumps studding my thighs. I hide them well,
most of the time. (VB1 14-21)
The image initially conveys the idea of being at odds with a body that does not conform to ableist ideals and acknowledges the desire to keep external evidence of physical and emotional scarring hidden. The observation “I hide them well,” is countered by the juxtaposition of the next phrase “most of the time” (VB1 21). These thoughts are momentarily subverted when Lambeth makes an associative leap to the image of Botticelli’s “Birth of Venus.” The comparison equates the luminous goddess of fertility and archetypal beauty with transformation: figuratively reborn, she emerges from the organza shell-like “silk encasement,” rising from the waves as the mantle of the dress falls away (VB1 27). The return to reality is indicated by “Then/ I see my body” as the speaker lists the coarseness of the imperfections which are “stippled” and “studding” the body’s facade (VB1 19-20).

“Coming Down” communicates the anxiety, stigma, the stain of discredited flawed bodies that are “dissonant” from societal ideals in order to contest medical and societal interpretations that limit the experience of chronic illness and the spectrum of disabled
embodiment (Diane Driedger and Michelle Owen 179). The fluctuating idealisation and objectification of the body manifests what Wendell argues is the “myth of control,” a “cultural desperation” to control the physical appearance and workings of the “uncontrollable” body (The Rejected Body 93-102). The concluding line emphasises the need to “let go,” that failure to recognise the limitations and imperfections of bodies places us in danger of erasing much of the reality of lived bodies: “from such a height/ you let go and eventually reach ground” (VB1 31-32). Letting go, becoming grounded in reality is a process of resistance and reclamation, challenging attitudinal barriers and exploring the “tension between the limits and possibilities of communicability in speaking about emotion and illness” (Scheuer 157). Dismantling the dress’s enfolding fabric represents the stepping outside the comfort zone of conventional thinking as a liberating experience. She observes: “I find myself between these two bodies —chairless, trackless, but unsturdily small-footed and weak-limbed. Not cut out for this sort of thing unless I change shape, redistribute myself into parts” (“Downhill” 5). Acknowledging difference and renegotiating these “parts” that have the potential to “change” into newly reconstructed forms is a liberating reconfiguration of societal expectation achieved within the spaces of her poems (“Downhill” 5).

**Conclusion:** “A different kind of cleric”

This chapter explores how Lambeth interrogates the boundaries of disability definition. By composing poetry centered on the real life experience of living with MS, she portrays responding to the intermittent effects of MS, erecting defensive protective layers that contain the sensations of touch and pain. Her concern is with exploring points of connection between physical experience and social, cultural relations, and the experience of being located in a particular space, place and body. Her poems shift focus onto the
spaces of the body rather than bodies in space and space itself. For Lambeth, the significant “gasps and tensions, contacts and separations” occur inside the body as well as between bodies (Lefebvre 184). Whilst Butler and Bowlby’s work, for example, investigates how “attitudes towards ‘disability’ affect disabled people’s ability to move freely within public spaces,” Lambeth’s poetry more often explores the interior spaces of the body and its interaction with other bodies in the more intimate settings of the home (“Bodies and Space” 411).

Lambeth conceptualises the highly subjective changes in the phenomenological experience of MS “bodily dysfunction” by making the disruption of space between the body and the world explicit (Toombs “The Lived Experience” 10). The spatial distribution of words disrupts the reading process and the performance of the poem in ways that represent dysfunction. According to Toombs the “dynamic relation between body and world, the phenomenological notion of the lived body provides important insights into the disruption of space and time that are an integral element of physical disability” (“The Lived Experience” 10). For Lambeth, however, the “disruption” is more closely linked to the body and its relation to MS symptoms; in particular, the neurological dysfunction which disrupts the signals from brain to sensory organs and to and from points of contact outside the self. When these signals are interrupted the “orientational and intentional locus” becomes ambiguous, reducing not just the mobility of the individual but the sensory perception of external spaces and “thus transforming the experience of space” (Toombs “The Lived Experience” 11).

By re-thinking the relation between the inside and the outside of the subject, Lambeth’s poems evoke notions of the body as complex, layered and multiple in ways that align with Kara Dorris’s observations on the body as text: “The body is a text with multiple authors—In this sense, we are all texts of erasure and all authors of erasure texts—
disabled or not. We overlay our own interpretations onto the bodies of strangers passing by, as they overlay their interpretations onto our bodies” (“Some Notes on the Body”). From this perspective, Lambeth’s “overlay” is a playful imprint of her body woven into the written fabric of her poetry: the experimental line length and stanza layout represent a diversity of bodily practices, erased “interpretations,” multiple “overlay(s)” and disparate encounters with others (Dorris “Some Notes on the Body”).

Writing about the disabled body enables its multifaceted nature to be explored. We are reminded of the fluid nature of embodiment when Jos Boys argues that the “boundaries between disability and ability are ambiguous and porous; and that disability and ability need to be explored together, not separately.” He observes:

[Dis/ability is therefore used to express such complex entanglements between and across all our many bodies, and to remind us of the endless overlaps and slippages between being abled and disabled. Spillages are most notable in the case of ill health as the body rapidly deteriorates and the user has to confront a loss of body functions with the experience of MS being no different (6).]

Lambeth’s concern is to challenge these “overlaps and slippages” of language which fail to communicate the diversity of bodily practices and encounters (Boys 6). In the article “Erasure as Reclamation,” Lambeth explains her thinking when approaching the retelling of personal periodic narratives:

Only here, it's a narrative of my body, of my brain, which I can only understand through the filter of a different kind of cleric: a medical professional who neither knows me nor lives in my body but can decipher it through language. And that's a bit curious, because we all know what power language wields. When the radiologist writes that “Lesions [are] too numerous and confluent to count,” I want to step inside those words. I inhabit them, anyway, don't I? (“Erasure as Reclamation”)
She positions her speaker as the voice of a “different type of cleric,” recording the distinctive perspective of one seeing through the “filter” of language, decoding the signs on the signifying surfaces from the “inside” (“Erasure”). Thus, Lambeth’s speaker literally and figuratively steps inside language on enjambed asymmetric metrical feet and broken poetic lines to create new relationships, unexpected perspectives and new meanings. She narrates from the inside: rather than letting herself be labelled and medicalised from an exterior conventional perspective, she constructs an “aesthetics that is at once somatic and social, shaped by the particular way in which each body encounters the world” through her poems and through the lens of space (Scheuer 156). From this alternative disability perspective, Lambeth conceives a different interiority from those that conventionally mark the boundary beyond the self as a site of exchange, and delimiting the “process of what we become by virtue of our ever changing relationship with the other, of our relationship with the outside” (Jean Starobinski 335). Her poetry brings the private experience into the public realm as part of an on-going and innovative tradition of making real bodies visible.
Chapter 4 Conclusion: Future Directions in Disability Poetics.

This PhD began with an examination of the representation of embodiment, space and poesis in the literary, political, philosophical, legislative and social contexts of American 21st century disability poetry. It frames its argument around the various ways Ferris, Kuusisto, and Lambeth expose the narrowness of traditional Western ideals of normalcy, making audiences rethink the spaces of the body and the relationship between depth and surface, between inside and outside and between self and other. My thesis responds to Weise’s plea, “I’d like to see more studies, within the field of poetry, that consider the long history of disability and literature” and does so by placing the selected poetry against the backdrop of temporal, economic and legislative change (“Disability Rights Movement”). I have shown how these domains are at the interstices where phenomenological and societal practices are brought into contact in different situational contexts: these meeting points are the crip contours, the formal or spatial correspondences, the outlines and boundaries where architectural, institutional, and cultural landscapes intersect with exterior corporeal surfaces and interior dimensions of psychical subjectivity.

My thesis explores how Ferris, Kuusisto, and Lambeth negotiate and reimagine shifting contexts and encounters of bodies between the liminal and interstitial spaces of and within a disability poesis. As read and vocalised words, the speakers articulate from a crip perspective, one which subverts and resists both dualism and monism, blurring boundaries of traditional binary corporeal conceptions. The non-linear nature of their poetics challenge the fixity of notions of embodiment propounded in prose. Ahmed’s discourse on the “materialisation” of the body is an example of rhetoric which pursues a single point, in this case, to persuade us that bodies are an “effect of boundary, surface and fixity” (Cultural Politics 9). In contrast, their poetry offers a plethora of viewpoints and “effect” in ways which test these fixed boundaries
They also test the limits of what is autobiographical and how we reconstruct experience through memory of our past and present selves. As May Sarton observes, “There is always some sleight of hand going on in writing autobiography” problematising notions of authenticity (224). Their poetry not only challenges us to reconsider what we think we know and how we know it, but how we can encode and articulate the experience. Through the creative imagination and poetics, their poems transform, de-familiarise and break free from the “boundary” of institutional, societal and theoretical oppression; they resist and fragment language of containment that defines and asserts control; and they make the “fixity” of perception ambiguous, fluctuating between the abstract, re-imagined and the real to emulate the unpredictability of lived experience.

Thus, in complexifying spatial relationships, their poems resist models which argue from a single overarching perspective such as Ahmed’s assertion that at the intersections “the join, the interaction of the two surfaces, is always a question of power” (Cultural Politics 4). Even when employing metaphors of “power,” oppression, containment and control, these motifs are often countered by other imagery sometimes even within the same poem. Their versatility extends rather than simply adopts concepts wholesale, ideas like Rosi Braidotti’s notion that the body is understood in terms of a folding and unfolding entity, a “folding-in of external influences and simultaneous unfolding outwards of affects” (156). Instead, they crip these perspectives and refuse to inhabit the limited spaces of normative conceptions or take the contours of the body for granted.

My study shows the importance of disability poetics in building links between poetry, bodies and space in the field of spatial studies. Writing a preface to Yeung’s book, Tally observes, “Spatially oriented literary studies have helped to reframe or to transform contemporary criticism by focusing attention, in various ways, on the dynamic relations among space, place, and literature” (Spatial Engagement with Poetry v). He argues that adopting a
spatial analysis allows us to think about literature as being based on the relations between its narratives and the spaces in which these episodic events occur. It can be a way of acknowledging shifting perceptions and abilities; that these shifts have cultural, political and social meanings and histories which are influenced by the spaces they inhabit and the temporal contexts in which they are expressed. Yeung confirms that the “human body, or figure, its sense experiences and their articulation in poetic language and form, is inherently spatial” (Spatial Engagement with Poetry 44). Reading from a spatial perspective helps us place ourselves in real and imagined spaces, creating “an eidos of the human figure, a presence in space that begins to define the significance of space” situating individuals in particular and universal spaces (Susan Stewart 197). Within poetry, space becomes the prominent entity it deserves to be; vocalised words become the means to create vision and reshape experience.

Following on from the temporal contexts within which Ferris declares that the canon of American disability poetry aims to “make space roomier” (“Crip Poetry”). I have sought to demonstrate how reading Ferris, Kuusisto and Lambeth’s work opens up our thinking about space, the spaces of the body and the spaces between objects in ways that could be productively used to analyse other modern poetry. Davidson’s focus on ideas of voice and space in avant-garde and contemporary poetry falls short of commenting on the distinctive voice of the atypical body (Radical Spaces of Poetry). I would like to conclude, therefore, by proposing areas for future studies where the representation of the atypical body in and of space in poems could be expanded beyond the parameters of my thesis. In particular, researching the spaces where audiences access poetry, the spaces which promote equality of access and representation in the publishing world, the spaces in and outside academia, and finally, the locating of these spaces in a global context.

If, as Ferris argues, a general aim of disability poetry is to alter disability discourse and make it accessible to those within and outside academia, then the evidence would suggest that we
need to continue to broaden its application (Bartlett et al. *Beauty is a Verb* 92). Although a contentious area, it could be perceived, for example, as a useful addition to studies in medical humanities, contributing to advances in the care of patients. It presents “distinct ways of recording and interpreting human experience, including the experiences of health and illness, of seeking and undergoing - and for that matter providing - medical care” thereby challenging normative ideas of able bodies which underpin medicine’s relationship with disability (Martyn Evans and Ilora Finlay 26). Raanan Gillon makes the connection explicit: “Literature, art in its various forms . . . all in some way illuminate one of the central medical ethics issues —how ought a doctor to live his or her life as a *good doctor*” (155). Lambeth offers a similar viewpoint:

A couple years ago I was invited, along with poet Jillian Weise, by scholar Harold Braswell to be part of his panel at a bioethics conference. His idea was that disability poetry can serve as the bridge between bioethics and disability studies, which makes a lot of sense. And with that, it’s easy to imagine the role of empathy for a reader extending to the medical professional. (Appendix 3 287)

However, we need to think beyond the academy and in other sub-fields such as medical humanities. It could occupy more spaces in English studies and world literature courses – not just in narrow disability studies modules but any module on poetry as this would indicate a far richer, deeper integration and equality.

Further study would also be useful, to compare poetic representation of space and disability poetics in other cultural and situational contexts. Kuusisto points out that change is only achievable as part of an ongoing flexible process, one which recognises the tension inherent in challenging ableist perspectives as part of a shifting continuum:

One of the interesting things about ableism is that whatever form it takes it occupies the future perfect. There will be time enough to make things right for the non-normals but not today. One may fair [sic] say “not today” is the motto of the thing. Non hodie in Latin . . .
Not today will we question our assumptions about the majority of bodies on the planet. Ableism also refrains from saying ‘maybe tomorrow.’ ("Those Old Contours of Ableism")

If “not today” then hopefully joining the conversations here is an important step in the journey towards a new “tomorrow.” To achieve this potential, albeit in small steps, more notice needs to be made of the media spaces occupied by contemporary poets on YouTube videos, podcasts, blogs, e-magazines and creative writing forums, for example, to support writers in their goal of making the voices and presence of minorities more visible. It means paying more attention to other forms of networks and contacts which create communities of collaborative writing and publication.

One of the main strengths of poetry is its accessibility as a form easily compressed and placed on the internet. Digital poetics has expanded concepts of web poems which are accessed through electronic archivist sites such as the Electronic Poetry Center (EPC), founded in 1994 by Loss Pequeño Glazier and Charles Bernsteinas. Glazier’s Digital Poetics: the Making of E-Poetries (2002) illustrates how alternative textualities and electronic spaces are created utilising the programmable nature of computers: digital experiments use hypertext, computer generated animation, generative or combinatorial approaches to create text, to create alternative visual, interactive, kinetic, code, holographic (holopoetry), and experimental video poetry. It enables audio recording, records visual performances and can also be interactive.

Similar to the way that public architectural spaces are adapted to accommodate ramps and lifts for easier access. Daniel Sluman, one of the editors of Stairs and Whispers argues “accessibility as a must, and something that needs to be integrated rather than a self-congratulatory add-on” (WG “Interview”). The opening up of new platforms and digital spaces on a global scale is potentially more inclusive in publication terms too. When Bartlett asks “Do we need more poets with disabilities? A resounding, yes!” her comment reinforces the
significance of including a wider environmental context (“Ethics, Poetry”). Ferris also notes that poetry helps maintain our fluidity of thinking and performs a distinctive role as a literary form of exchange in a global context:

It’s impossible to truly engage with a good poem and not be changed a little, and not have a new sense of how someone else feels in the world. And each of those experiences add[s] to our sense of what is possible in this world of pain and promise. (Appendix 1 271)

This view is reflected in the importance of print based publications and anthologies like *Beauty Is a Verb* to effect change and reach wider audiences as Bartlett notes:

I think publishing in poetry is inherently biased; it always will be . . . disabled people are not regarded as a minority. So, when anthologists, editors, and teachers work to include race, gender, and sexual differences, disability is left out. This happens often. But things are changing and I want to be sure to note that. (“Disability and Poetry” 276).

The field of disability poetry is one of vibrancy, diversity and exciting poetic developments, which is expanding and changing all the time. It is important to track its developments and expand our understanding into other elements like performance poetry or how disability poetics aesthetics can be a useful addition to poetry courses, not just those on disability topics. Whether directly inspiring political action or by shifting our thinking on embodiment, poetry enables a variety of voices to express how individuals move, engage and feel in familiar and unfamiliar times and spaces:

Many people are drawn to poetry as a genre because it represents a space where private sensations and emotions are valued, and these online forums are accessible to a large and diverse audience. Therefore, a focus on lyric poetry allows communities to negotiate the tension between expressions of unity and recognitions of difference—a tension that remains critical to Disability Studies and politics. (Scheuer 163)
We only need to widen the scope to other modern anglophone disability poetry to realise that such progress is fragile.

Alongside the American anthology *Beauty is a Verb* (2011), the recently published *Stairs and Whispers: D/deaf and Disabled Poets Write Back* (2017) offers a uniquely British perspective, its cultural influences, the spatial dimension of body representation, and the environments of inner spaces of the home and workplace as spaces of activism. The words “Write Back” in the collection’s title indicates the political dimension to poems written by a community of Atos poets producing an online anthology in protest to the UK Tory welfare cuts. Sluman and Mark Burnhope compiled verses that attacked legislative changes in welfare citing the damaging effect of using economic policy as a new norm of categorisation and compilation. Burnhope observes, “*Fit to Work: Poets Against Atos* is an online database of ‘poets and punks, scribes and scroungers’ protesting against the co-operation of Atos Healthcare” (138). It responds to the way the British Disability Discrimination Act (DDA, enacted in 1995) is undermined by the post-2010 coalition government’s stringent enforcement of welfare assessment.

Poems such as Sluman’s “Shove Ten Pounds of Sugar in a Seven-pound Bag (A Manifesto for Disability Poetry)” represent these concerns as a public declaration of intent and poetic agency (*Stairs and Whispers* 19-23). But it also shows how these poetic conversations are not purely instrumental tools in the service of political ideology. The following lines are taken from Sluman’s 124 line poem which form 6 sections of verse. The opening stanzas challenge us to think about the agency of poetry as a genre, the words and spaces on the page, and the limits as well as the possibilities of space to represent what for Sluman is the “implicit leakiness of disabled bodies” (Appendix 4 294):

the poem is an artefact

made from words
& the space that exists
between & around the words

the spaces
are the negative of the words
part of a reciprocal
dialectic relationship
with the words

(without the spaces
there are no words)

* (SW19 1-11)

The first line statement “The poem is an artefact” asks us to reconsider all poetry and not just the specific one present (SW19 1). The speaker comments on how poetry provides the meeting points of the personal and the political, allowing access to interior spaces through a “reciprocal/dialectic relationship” (SW19 7-8). When I interviewed Sluman, he outlined that one of the main motivations behind his poetry is to capture the “physical absences and gaps of my body, from the very cathartic lack of a leg, to the gaps in my hip muscles due to underuse, or the absences of matter in my spinal vertebrae that cause me pain, (that) are for me, both physical and semantic at all times” (Appendix 4 291). The lack of formal punctuation in “Shove Ten Pounds of Sugar in a Seven-pound Bag (A Manifesto for Disability Poetry)” draws attention to the way words seem to pour down the page like sugar from a punctured bag. The speaker’s focus shifts to the conceptualisation of spaces in and outside the body:

i am human
the shape of my body exists within space

there are gaps & absences within & around my body every human has a unique set of absences created by their body

(without the absences there is no body)

* (SW19 12-20)

The image of space as “gaps & absences/ within & around my body” emphasises the disconnect between disabled and non-disabled experience (SW19 16). The speaker expands contemplation of the spaces where disabled bodies are absent, under-represented and erased by political discourse. According to Sluman there is a lack of engagement with disability in society and media discourses: “There is not only a real lack of knowledge about the types of lives disabled people like myself live, but there is also a lack of desire to understand these lives”(Appendix 4 292). The poem frames the space of the body as a contested site of reality and imagination centred on the testing and re-cataloguing of medical conditions implemented by government enforcers. In these physical spaces of government offices, the domestic setting and the workplace, the individual’s dis/ability is tested by non-medical professionals in response to an economically motivated government policy. As members of that society, we (sometimes innocently) turn a blind eye to what is “apparent” in front of us:

my absences are perhaps more apparent
The spaces alluded to are the literal space of the amputated leg and the societal spaces where prejudice and policy remove individuals from the mainstream, cutting off their access to funding and economic independence. In these spaces of “absence” Sluman exposes “how space can be made to hide consequences from us, how relations of power and discipline are inscribed into the apparently innocent spatiality of social life, how human geographies become filled with politics and ideology” (Soja 6). These spaces enable the poet to occupy the space of the page and give a personal voice where there is no public consensus. The speaker states “I am a walking signifier,” an emblem of economic policies, a figure that society attempts to erase:

the absence forces you
to ascribe meaning to it

forces you to project
your own emotional /
intellectual self
within the absence
(mommy why has that man’s leg fallen off?)

i am a walking signifier

* (SW20 34-42)

Sluman crip government policies satirising how spaces on the page are indicative of the gaps in public and private representation. His poetry brings disability into view:

My poetry is all I can do to give the reader the opportunity to understand how different the disabled experience is from a non-disabled one, and how social narratives often deny the disabled body the freedom we all deserve. (Appendix 4 291)

He notes that these “absences” of the disabled figure are replicated by under-representation of the genre in general. Poetry becomes the vehicle through which to project societal failings. Sluman’s remarks on disability poetics are telling: “Poetry is directed perception. It’s not about the words, but the space between the words; the best literature lets the reader fill in the gaps, lets them write the work themselves” (Brown). Sluman’s poem invites comparison of the interconnectedness of personal expressions of embodiment and agency within the dynamics of British legislation. It exemplifies an ongoing role in developing awareness of the relationship between individuals and the spaces they reside. Such rich contemporary disability poetry is worthy of future study.

In my recent interview, Ferris reflected on the progress made from writing his landmark essay “Crip Poetry, or How I Learned to Love the Limp” (2006), with which this thesis began. His thoughts about how disabled individuals are perceived are placed within a widening global context: “Real progress has been made; at the same time, there is so much more to be done” (Appendix 1 267). Indeed, more needs to be done to make disability poetry more visible on shelves and online, accessed and analysed by theorists, policymakers and academics, in the
workplaces, libraries and homes to ensure its presence rather than absence. Ferris is hopeful of change:

I think the accessible nation is achievable, but I think continuing to that goal will require something akin to a change in paradigm: the recognition that access is not about some of us but about all of us. (Appendix 1 272)

If disability is posited as a universal state of being that we all have in common as our bodies age over time, then we are more likely to respond to alternative visions of humanity with disability at its centre. Ferris’s “Poet of Cripples,” for example, represents this idea of an ideal future space in which policies of equality and inclusion evolve from an acceptance of disability embodiment as a collective identity:

Look with care, look deep.

Know that you are a cripple too.

I sing for cripples; I sing for you. (HPix 12-14)

The repeated direction to “look” invites readers to scrutinise our laws, literature and language in a broader sense (HPix 12). The second person address urges us to recognise our joint responsibility and actively find the answers “deep” inside ourselves (HPix 12). The circular structure is reinforced by the way that the final line returns to the title and the poem’s opening word, “cripples” signifying unity (HPix 14). The climactic end-stopped rhyming couplet finishes with the resonant inclusivity of “you/ too” and shifts the perspective to the reader’s inclusion (HPix 13-14). Ferris’s atypical lens reformulates the world he inhabits, examining his relation to others and other objects who challenge his sense of self and those of the disabled community.

Evaluating attitudes to disability in society, Ferris reflects that events during the Covid 19 pandemic (2020) highlight that disabled individuals continue the fight to be valued:

I know that when it comes to deploying resources (like who gets to use a ventilator and who doesn’t), I don’t want those decisions made by people who think that the lives of
people with disabilities are not worth living. I want those decisions made by people like you, people who are committed to recognizing the value of every life, who are committed to learning and doing the work to maintain the systems that disabled people and everyone else need to live a full life. (Appendix 1 268)

Responding to this emphasis of monetising our value, Ferris aims to engage in debates on disability through creating poetry that shifts the definition of what it means to be a citizen. These concerns are just as pertinent today as disabled individuals remain at risk from contemporary hierarchies of power. The Covid 19 coronavirus pandemic highlights government and public health policies which prioritise lifesaving equipment contesting the value of certain individuals within society. The health crisis has a deeply spatial element as governments determine who is allowed to access public spaces. Ferris comments:

Disability culture is ignored at best, misunderstood or maligned. If we just look at how people are being positioned during the current coronavirus pandemic, disabled people are again among the last to be considered . . . And now social distancing to control the spread of the contagion. I don’t resist that distancing, because it seems like an important part of controlling the viral menace. And yet we are once again being taught to fear our fellows, carriers may not even know they are infected. You may already have won—or lost.

(Appendix 1 271-272)

For Ferris, Kuusisto and Lambeth, poetry reflects the lived experience of disability in ways which offer a more nuanced understanding of predefined political and social constructs, inverts or transgresses outdated ideologies and brings disability experience into the public domain. The questions that this thesis poses, therefore, are about opening up public spaces, about its potential within other fields such as disability rights and medical humanities, and the centrality of its place in other literary fields. In fact, in thinking about how space connects poetry to real situations, lived experiences and politics, greater cognisance can be taken of the various spaces which disability
poetry inhabits, its diverse communities and conversations, including those located inside and outside academia, traditional publishing companies and policy making institutions.
Appendix 1: Jim Ferris Interview

**TF:** Your landmark essay “Crip Poetry, or How I Learned to Love the Limp” (2006) has been widely acclaimed for its initiation of the debate on the function of disability poetry and its potential agency in challenging conceptions of disabled individuals. What progress do you see having been made 20+ years on from the original points made on how disabled individuals are perceived by society?

**JF:** Some progress has been made, to be sure, though disabled people around the world continue to be subjected to oppression, ranging from violence and abuse to the “softer” oppression of low expectations and limited opportunities. Disabled people have been able to claim more of a place in many societies: more than a hundred countries now have national organizations of disabled people, disabled people are somewhat less likely to be restricted to back rooms and institutions, and somewhat more opportunities for education are available. Real progress has been made; at the same time, there is so much more to be done.

Disability culture is ignored at best, misunderstood or maligned. If we just look at how people are being positioned during the current coronavirus pandemic, disabled people are again among the last to be considered. The current reassurances that are being offered: “Be careful but don’t worry, old and sick people are at most risk.” Disabled people is what they mean. “Don’t worry, it is most likely to kill the people we are least interested in saving anyway.” This is not to overlook the work that many nondisabled as well as disabled people are doing to safeguard vulnerable disabled and chronically ill people, but to the society at large we are still easily overlooked, a nuisance or worse. I told my Disability Studies students this week “This is not a drill. Situations like this—life and death situations like this—are all about disability, and they are exactly why the work we do in Disability Studies is so important. I was speaking with a friend yesterday who suspects that with her compromised immune system she will not survive this
pandemic. I know that when it comes to deploying resources (like who gets to use a ventilator and who doesn’t), I don't want those decisions made by people who think that the lives of people with disabilities are not worth living. I want those decisions made by people like you, people who are committed to recognizing the value of every life, who are committed to learning and doing the work to maintain the systems that disabled people and everyone else need to live a full life.” As I noted above, I do think we’ve made some progress, but there is so much more that is needed.

Maybe this is the heart of the problem: nondisabled people don’t recognize that disabled people are the most creative people on the planet, because we have to be. When the water rises, when the electricity goes off, disabled people have to be creative and determined and imaginative and help each other out, and then do it again tomorrow, because we live in an ableist world that isn’t even perceptive and imaginative enough to recognize the huge contributions disabled people make just by living every day. If you want to figure out how to get something done, how to solve a problem, how to work around barriers, ask a crip. They think the blind leading the blind is a bad idea, but who knows better how to negotiate the world as a blind person? To quote the great Mr. T from “The A Team,” “I pity the fools”—but I also know to be wary around them.

TF: In the essay you add that crip poetry has “the potential to transform the world, to make the world in which we live roomier.” Can you indicate the different ways you consider your poetry attempts to achieve this aim and/or communicate this process?

JF: I hope that my poems help to create a space in the social consciousness for disabled people to be—and be recognized—as full, whole human beings. I hope my poems assert the rich and fruitful presence of a wide range of ways of moving through the world. Some of my poems advance an explicitly disabled persona using language to engage with complex world. An example is “How We Swim,” which is on one level an elegy for the late scholar and activist Paul
Longmore, while on another level it is about disability activism and the disability rights
movement—about crips insisting that we belong in the world. Other poems may seek to poke
holes in the tissue of attitudes, assumptions and practices that serve to otherize and impinge on
the humanity of disabled people. Still other poems are not “about disability” in any overt external
sense, but the simple presence of poems by a disabled poet helps to claim space in the world for
disabled people and their rich and varied perspectives.

I also recognize that my disability experience deeply informs how I encounter the world,
how I think and feel as I inhabit each day in whatever place I am in on this complex planet. I am
using that disability experience whether I write “about disability” overtly or not.

**TF:** Your essay also discusses how your writing aims to “validate the lived experience of
moving through the world with a disability.” Can you elaborate on your choice of imagery and
your use of spatial motifs in general? Perhaps you can also touch on how the typography and
verse form of your poetry is used to replicate the negotiation of different types of real and
imagined spaces?

**JF:** What the poem looks like on the page, and what it feels like in the speaking, hearing, and
reading are all part of the music of the poem. And music is always different from space to space,
from the shower to the living room to the concert stage to the recording studio. I hope my poems
create the opportunity for some space in the reader’s or listener’s mind, which is not separate
from the body. Opening space for experience, making a bit of space for this moment, as fleeting
and precious and irreplaceable as it is. I think more consciously about voice than about space in a
poem, usually, but sometimes a poem just has to have room for the air to get under its wings.

Typography, line breaks, stanza breaks, indentations, columns—I try to make use of all
the tools available to create—to open, to allow, to engender—the effect I seek. Or some effect.
The word is not the thing, the map is not the territory—but each word is a thing, the words
together are both things and a thing, each poem is a territory. I hope my poems create or allow
room for people to move around in. Everything is a happy accident; nothing is by mistake.
Except for mistakes, which I will realize later.

**TF:** So, for example, the poem “Exercise of Power” describes how visible forms of “God’s mistakes” need to be fixed. Which poetic techniques do you most consciously employ to convey the visibility of your disability?

**JF:** Line lengths and the deployment of white space on the page are the chief techniques I use to reflect something of my atypical perspective. There is an interesting conflict between conforming to the generic expectations of what a poem should look like and trying to create for the reader and listener an experience that reflects what I’m seeking to engender. In a real way the poems are not about me. They may draw heavily on my lived experience; they are certainly shaped by my thinking and feeling and sense of language; but for a poem to really work, it has to in some way not only be accessible to the audience but also to be in some unexpected way *about* the audience. I hope my poems create an experience for the audience. And when my poems are really working, they stop being mine and they become *yours* and *ours*. There may be times when I need the audience to read a poem with my impaired body in mind, but mostly I hope to push past that, maybe, ideally, somehow with their own once and future impaired body in mind. Or in *bodymind*. It’s always good to remember that bodies and minds are not separate things, however much we yearn to give in to the restrictions and narrownesses we have been taught.

**TF:** Your wonderful poem “Poet of Cripples,” refers to how crip poetry enables readers to reconsider the “space to grow in ways/ unimaginable to the straight/ and the narrow, the small and similar.” Can you indicate more about how you see poetry as an aid to this process? How might your poetry be thought to be an expression of embodiment as a varied, fluid shape, allowing individuals to expand their notion of different bodies?

**JF:** Poetry offers readers and listeners new opportunities to feel, think, experience something in this world that we share. When we’re lucky, poems give us not only new opportunities but new
ways of feeling/thinking/experiencing. It’s impossible to truly engage with a good poem and not be changed a little, and not have a new sense of how someone else feels in the world. And each of those experiences add to our sense of what is possible in this world of pain and promise. I’m probably mangling someone else’s concept, but I think of the cultural imaginary as this giant storehouse of all the images and associations that are available within a particular culture.

Each poem, as well as each other form of art, has the potential to contribute to that great cultural storehouse of possible images—which includes possible ways of being in the world. Each time we contribute to that great storehouse, we have the potential to enlarge the range of what is possible to imagine in that culture. Poems can help make the world more possible. What could be a greater gift than that?

**TF:** I love your poem “Return to the Ward” where the persona experiences a sense of dislocation: patients navigate the closed off world of the hospital juxtaposed with exposure to life outside. In what ways do you consider your poetry helps us to understand how we exist in public and private spaces? How do you use poetry to challenge our thinking about how spaces operate and are designed?

**JF:** Thanks for nudging me to reread “Return to the Ward.” I wonder what has become of the guys I came to know well during my many stays on the ward. I also find myself thinking about the distancing we experienced, that was a central part of that experience - especially in light of the direction for social distancing as I write this in the face of the coronavirus pandemic. And I wonder how different they are. Distancing at the charity hospital was in part about infection control, ostensibly, but it may also have been about sheltering us or quarantining us away from a society that was afraid of us, even though it might not want to realize let alone admit it. And now social distancing to control the spread of the contagion. I don’t resist that distancing, because it seems like an important part of controlling the viral menace. And yet we are once again being
taught to fear our fellows, carriers may not even know they are infected. You may already have won—or lost.

The way poems lay out on the page can be a challenge to the conventional ways spaces are designed and operate, not unlike the exciting dance that Alice Sheppard and her collaborators are doing. What else can we do with this space, with this page? It can be fun to find out. Generic expectations give us boundaries to lean on as well as to push against. When does a piece of writing cross from poem to prose or monologue? Or visual art, painting, sculpture? Interesting question, even if it is ultimately constricting. But constriction is how the boa eats. Feed me.

**TF:** The poems in your second collection *Slouching Towards Guantanamo* (2011) can be interpreted as documenting the establishment of an imagined disabled nation space. 30 years after the ADA, in what ways do you still think the accessible nation is an achievable reality or a distant utopia? How do you think your own crip poetry has to evolve in the next two decades in order to continue to help make the case for society to be made more accessible for disabled people?

**JF:** I think the accessible nation is achievable, but I think continuing to that goal will require something akin to a change in paradigm: the recognition that access is not about some of us but about all of us. This feels comparable to me to the people who may recognize that climate change is happening but who think that it’s really somebody else’s problem. It’s really all of our problem, and access is all our problem and opportunity as well.

How does my own poetry have to evolve? I’m not sure evolution is best planned; and I am leery of attempts to engineer a better poem—or poetics. Progressive ideals gave us eugenics and prohibition along with woman suffrage and educational reforms. Greater access and opportunity for disabled people is a crucial goal, but for poems to work they can’t be propaganda. And we have to be careful about being too directive with these delicate but powerful things.
TF: Your poem, “Manifest Destiny,” for example, cites many political and cultural references from various people and periods of American history. I was wondering if you could share your thoughts on representing the shift in societal representation of embodiment through historical citation.

JF: I wrote “Manifest Destiny” in response to an unvoiced challenge from the Iraqi poet Saadi Youssef. I was reading Khaled Mattawa’s translation of Youssef’s poem “America, America” on the eve of the US invasion of Iraq. I had joined thousands in marching to the state capitol in Madison to tell the US government not to start another war, not to indulge the blood lust that we too often are pulled by. While reading Youssef’s poem I was struck by his embrace of my country and its ideals while not holding back for a moment from his clear-eyed critique of our failures to live up to those ideals. I was also struck by his use of a refrain drawn from patriotic song, which led me to the idea of drawing upon American commonplaces, images and phrases so central to the American mythos that they would require no citation. I think I was wrong about the 1968 quotation from Chicago Mayor Daley, by the way (“the policeman isn’t there to create disorder, he’s there to preserve disorder”). But the power of those commonplaces, at least for those of us who grew up on them—and maybe for Youssef—is compelling. I read that poem at a poetry reading at a university in the American South just a couple weeks ago, and it still has power for me: at one point toward the end of the poem, I always feel like crying. Recognizing both our recurrent, deep, pervasive failures to live up to our ideals, while still asserting the hope in the ideals—that was the challenge from Youssef. Maybe someday I will get to show him the poem.

TF: Are there any particular philosophers, disability studies theorists or perception phenomenologists who have consciously influenced your work; and how have they influenced your thinking?
JF: Consciously? No, not really. I find myself using ideas and language from existential phenomenologists like Merleau-Ponty, but I’m leery of too explicitly committing to any theorist’s ideas—I think I’m afraid that will inhibit the poem from jumping wherever the hell it needs to go.

Disability studies theorists present another question, I think. Disability studies is still something of a cottage industry. The field has grown by leaps and bounds (running with the jumping metaphor in the paragraph above), but it is still relatively small. It was never quite true that we all know each other, and less true now, but the ideas that constitute disability studies theory developed in community and collaboration among a bunch of people trying to puzzle our ways through thorny questions. I think it’s fair to say that most everybody who might qualify as a disability studies theorist has helped to shape and enrich my thinking; I hope I’ve given as good as I’ve gotten.
Appendix 2: Stephen Kuusisto Interview

TF: A major part of your writing is focused on the representation of city landscapes and the processes of traversing unknown spaces. Can you tell us more about how you envision the public spaces of the city function as a way of defining subjective experience in your poetry?

SK: The city is of course the proscenium arch of modernism. Cities are where the flaneur and the café both flourish. Walt Whitman’s Manhattan is both literal and figurative, sacred and profane, real and imaginary. Modernist poetry starts with Baudelaire and Whitman. As a blind traveller I find cities are easier to navigate than rural spaces. I often tell people that New York City is very easy to navigate when you’re blind. But aside from ease, cities are also remarkable for their surprising incitements: one discovers in Venice a group of intoxicated men trying to push a garbage scow under a bridge while singing; a policeman talking softly to his horse before sunrise in Helsinki; cities are places where chance dramas are more apparent. So of course in this way they’re great subjects for art.

TF: In your memoir, Planet of the Blind (1998) you say: “On the Planet of the Blind, no one needs to be cured. Blindness is another form of music.” Can you indicate the ways you consider your poems are consciously constructed to convey this notion? How do you set about representing how you visualise and interact with the real and imagined spaces of different cultural environments?

SK: I always resist the medical model of disablement and to the degree my poems are polemical that would be the heart of it. Disability is rich in literal and figurative experiences and this is why so many great artists have been influenced by bodily inconveniences, Monet with his failing vision, again, Walt Whitman writing after his strokes, Jackson Pollock’s clinical depression—disability is everywhere in art once you learn to look for it. As for me, I know that my visual experiences are inherently beautiful though wildly inexact. I “work this” as they say in the
vernacular. This is as much a political engagement as an aesthetic one: the blind are possessors of beauty and wisdom.

**TF:** *Planet of the Blind* also makes reference to the notion of a “sensorium of the blind” as possessing “some marginal vision” that is “by turns magical and disturbing.” In what ways do you consider your poetry helps us to understand how we exist in public and private spaces and challenges how spaces operate and are designed?

**SK:** When journalism adopted the news photo as an adjunct to print story telling the notion of reportorial language became tied to the photographic image. Seeing a dead dog beside railway tracks Ernest Hemingway leapt from his train carriage and wrote every detail about the dog’s corpse into his notebook. When people ask me “how can you write so vividly about the world if you can’t see?” what they’re really saying is, “isn’t language just a sub-genre of photography? The surrealists understood that you can say things in poetry that can’t be pictorially represented—Monday blazes like a wheel, the poor live inside the casket of the sun. As I’ve hinted above, my goal is to show how interesting a blind life really is. And I’m helped by my visionary and surreal ancestors.

**TF:** Are there any particular philosophers, disability studies theorists or perception phenomenologists who have consciously influenced your work; and how have they influenced your thinking?

**SK:** Well I suppose a number of writers have had an influence on my thinking: Gaston Bachelard; Merleau-Ponty; Husserl’s *Logical Investigations*; but I must also reference poets as diverse as Yeats; Auden, the great Surrealists like Lorca and Neruda. Disability Studies has seemed to me un-nutritious most of the time, reactive and polemical rather than speculative and probative, though I’m fond of any work proposing disability as epistemology.
TF: Can you also tell us more about how literary figures such as Allegri Dante and Jorge Luis Borges, for example, interest you as literary guides and inspire your poetry’s imaginative landscapes?

SK: Both were visionary poets much in the manner of the English Romantics with whom they are not customarily identified. The visionary poet tends toward imaginative experiences that can’t be drawn or photographed. What could be better for a blind writer than to have permission to not be a journalist?

TF: I love the way the poem “The Books to Come” presents readers with a future vista notion of real and imaginary geographies of space. Can you elaborate on what ways you think books help us imagine the future world and the spaces that we will inhabit? Do you see any distinctions in the ability of prose and/or poems to achieve the same end?

SK: Borges imagined Paradise would be a library and there is something of the vatic about reading. One way to think about this is that the very act of reading—the first effect of literacy—is that the reader is granted the opportunity to question the language itself. All readers are contrarians or at least all good readers. This why tyrants want to burn books and imprison intellectuals and its why Shakespeare’s audiences could experience comic or tragic irony, that sense we have that we know more than the characters on the stage. In this way all literary writing is an invitation to step outside our customary thinking. In terms of geography one may think of reading as a visionary invitation to be productively lost. I think poetry and prose can both deliver this.

TF: In “Books to Come” you also remark that books are “Likely /To save us /Like secret friends, /books to come.” I love this idea of future writings juxtaposed with the citations from the past. In what ways do you believe your own poetry sets about contributing to a future vision of society? How do you consider your poems give voice and help make the case for society to be made more accessible for all?
SK: I think all creative writing has the capacity to be utopian. This does not mean I believe all writing achieves it. When we read Rilke or the best of Auden we’re in the presence of aspirational loveliness which is another name for hope. I believe in this.

TF: In the poem, “Letter to Borges from London” you recount the speaker’s perception of as a constructor of imaginative spaces: “Now I’m a natural philosopher but with the same restless hands. /Some days I put cities together –.” Can you elaborate on your choice of imagery and your use of spatial motifs in general? Perhaps you can also touch on how the typography and verse form of your poetry is used to replicate the negotiation of different types of real and imagined spaces?

SK: I think that urban designers, architects, city planners are often so hopelessly utilitarian (what will be cheapest and serve the most standardized people?) that they miss out on the possibilities for public space. Inclusive spaces need not be expensive or ugly—I love the idea of a Kyoto of universal design.

TF: As you are aware, nearly thirty years ago, the Americans with Disabilities Act (ADA) was introduced. How do set about representing the shift in societal representation of embodiment through your poetry?

SK: Behind all my poems is the vivid assertion that I belong in the public square. Moreover sometimes in a poem I can be rather militant about it.
Appendix 3: Laurie Clements Lambeth Interview

**TF:** You have said previously in a blog entry for the National Multiple Sclerosis Society that you are interested in invisible disabilities: “One of my interests is invisible disabilities…. I feel invisible and hypervisible at the same time” (“Laurie Clements Lambeth”). I believe this is still such an important area of concern and tension that it is worth revisiting. Could you perhaps expand on what you mean by this concept and suggest ways you convey the notion in your poetry?

**LCL:** My form of multiple sclerosis is relapsing-remitting, on the cusp of secondary progressive. I sometimes drag my leg, sometimes use a cane, and sometimes walk with ease (with the help of a muscle relaxant and anticonvulsant). I often don’t appear to have a disability at all, even though I may be very tired, have trouble with my cognition, have difficulty swallowing or speaking, feel dizzy, or not sense when my bladder is full. My glasses are tinted to help with glare from Optic Neuritis years ago, but people just think they’re sunglasses. In essence, I often pass. Living with an invisible disability, or multiple invisible disabilities emanating from one disease, can make me an object of suspicion, that somehow I am trying to benefit from accessible parking, or an accessible toilet, or that somehow I am lying, and it can also render me a curiosity.

At the Tate Modern I was almost denied an electric wheelchair because they’re for people “who are really disabled.” Conversely, when my hand doesn’t work but the rest of me appears to, and a cashier offers me change in that hand, they don’t know that I can’t sort the coins and bills. And then I hold up the queue, becoming more visible, with other customers’ diagnostic gazes trying to figure me out: what is wrong with her? The diagnostic gaze makes you hypervisible because you don’t fit the image a person has of disability, or of non-disability. You’re just a walking, standing question. This brings us back to what compels me about Wittgenstein and Scarry: people outside a disabled person’s body and mind will always approach the disability or
pain with doubt, because they do not feel it. One of the first films ever produced is Edison’s 30-second “Fake Beggar,” and we haven’t moved far from that mindset of suspicion and disability performance in the intervening years.

When it comes to my MS-related cognitive challenges, it gets more complicated. I appear able bodied, young enough, and educated, and I am of course a writer, so language should come easily. Sometimes the wrong words will replace other words in my mind, and they will do so persistently, even though they are definitely not what I mean to say. Unaware of this until later reflection, I find myself at sea, and I imagine whoever I said it to is probably similarly confused. Sometimes it takes a while to say what I want to say and gather the words into a sentence. People often don’t have the patience for this. Once again, I don’t fit the concept of disability or non-disability. When it comes to cognitive difference I find I am more often dismissed than crafted into an object of curiosity. But it drives my curiosity, nonetheless.

I imagine this liminal state of visible and invisible disability brings me to poetry. I want to investigate it because the experience feels so entirely internal, reminding me that others do not understand my physical state at all unless I share it. Sometimes I don’t understand it either, so I bring the question to the page and the poem offers answers I may not have anticipated. So the poem (or essay) is both a place I go to express disability encounters or changes and to find out what they might mean.

**TF:** In your essay “Reshaping the Outline” in *Beauty is a Verb* (2011) you say that “Poetry helped me investigate and reinforce the blur I felt between body and world, and gave me the space to insist upon the bounding line's fluidity.” This is a fascinating concept. I am wondering if you could say more about how you feel poetry offers a medium to explore these ideas on representing blurring boundaries.

**LCL:** Poetry can provide an immediate experience of a different body for readers, moving them outside of their own bodies and into that of the poet, feeling something akin to what s/he feels.
Hopefully, it can contain the power to move readers into that blurred state, into uncertainty and perceived shared feeling, which, if they choose to go, could help bridge communities. Hopefully.

In the events described in “Reshaping the Outline,” my consciousness of that blur came after I felt it. I felt an absence of sensation that opened my body up to the environment around me. I became permeable.

The concept of tenor and vehicle in a metaphor has been absolutely blurred in much of my poetry, and I once spent a very uncomfortable hour alone with a famous visiting poet who berated me and my work for the lack of distinction between tenor and vehicle. It wasn’t until later that I discovered that this blurring is a quality that makes my work unique. But there are still Important Poets who don’t connect to that, and readers who might not.

**TF**: In your earlier interview with *The Atlantic* “‘Hurtful and Beautiful’: Life with Multiple Sclerosis” (2012), you remark on the ability of your mind to help you create poetry to represent the experience of MS: “I like the idea that the wound is the blessing that leads you to create. It’s hurtful and beautiful at the same time.” How do you think your own poetry helps make the case for society to be made more accessible for all?

**LCL**: I would like to help society perceive disability and difference as beautiful. In the previous paragraph of the interview, I mention, “having some perceptual walls broken down […] helped me become more aware of the body's variability and oddness.” I hope that those walls can be broken down for readers, so that they understand—whether they are temporarily able-bodied or disabled—that physical certainty is a myth, and that they, too, exist in a variable sense of time and ability, a fact that could be accepted and celebrated, rather than feared and cured. This mind-frame might not immediately make society more accessible, but it could help people understand that access for disabled people means access for themselves at any time, and that the barrier between disability and what is considered the norm is elastic and potentially broken, which is okay, just a new way of dwelling in the world. And if the world is more accessible and open to
the multiple modes of accessibility, then that new way of dwelling in the world will feel more natural for everyone.

**TF:** The poem “Coming Down” explores the experience of being undressed and the intimacy of touch. The private domain of the bedroom is exposed into the public world of poetry. In what ways do you consider your poetry helps us to understand how we exist in public and private spaces and challenges our thinking about how spaces operate and are designed?

**LCL:** This is such an interesting question. That poem also unites the public event of a wedding with the bedroom, the private space of the fitting room at I Do, I Do, and finally the outdoors, bringing us to the feeling of climbing off of a horse. That’s kind of why it is the first poem in *Veil and Burn*, because it encompasses multiple strains or motifs that reverberate throughout the book. It’s quite a bold introduction, though. Its space within the book is thereby foregrounded, placing the bedroom and intimacy in the space of a foyer. Putting the next collection together, I am faced with similar challenges, wondering what constitutes the best entry into the world of the book. The space of the body is of course another space we occupy, and I kind of want to argue that this is the most private space, the internal life of the speaker with her doubts and her fascinations and love, with her disability and independence (getting out of the dress without help) and desire, a space readers can inhabit. The poem serves as an invitation to a very intimate form of empathy. In this and other poems, such as “Hypoaesthesia,” I also want to show that people with disabilities are indeed sexual beings, deserving of touch and desire, while hopefully insisting upon the agency of the disabled speaker and her experience, rather than objectification.

**TF:** When discussing “Seizure or Seduction of Persephone” you indicated a “gutter down the middle of the poem” is a key spatial feature and metaphor for representing the subjective experience of MS. I love how the spatial divides help represent the breaking of the persona’s body and the displacement of surfaces and bodily contours. Can you elaborate on your choice of imagery and your use of spatial motifs in general? Perhaps you can also touch on how the
typography and verse form of your poetry is used to replicate the negotiation of different types of real and imagined, internal and external spaces?

**LCL:** I’m very much the kind of writer who learns the rules in order to break them. I enjoy writing in form and love letting poems find their own shapes. Reading May Swenson for the first time, particularly her poem “Bleeding” with its gutter, just blew me away. I thought, I want to do that someday. And really, that kind of interrupted line goes back to the Anglo-Saxon caesura, but it’s more fluid in contemporary poems. The gutter alters the way I read a poem aloud, too, because it offers two potential enjambments per line, a tiny pause. Those enjambments then expand possibilities, with each half of the line, at its best, striving towards being its own unit of meaning.

Did you know “enjambment” comes from the French *jambe*, meaning leg? So a line break without punctuation is like taking a step. Richard Howard used to tell us (having translated Proust and Baudelaire), that an *enjambment* (*en français*) is the moment one leg has stepped and the other knows to start its next step. But that’s a completely different experience for people with disabilities, so why not disrupt it and play with it? So definitely, line length, gutters, prose fragments, stanza breaks, and enjambments serve as opportunities for me to contemplate the body, the space of the page, and breath—all that air around and within the poem. And stanza breaks—for instance, couplets—allow individual lines more space around them to shine and open up potential meanings. The space around a poem compresses it and lets it breathe, and the formal choices the poet makes help her whittle it even further. And more, the placement of poems in a book allows the poems to contribute to larger moods and meanings, bringing continuity or friction, generating new meaning, giving poems that may seem minor to the poet greater prominence. That space is so important, the leap between poems.

Are you familiar with Alan Grossman’s *The Sighted Singer* (1992)? In it, he posits that line lengths are related to the kind of material or mood of the poems themselves, with a short line
being more private, a long line, like Blake or Whitman, being more expansive and possibly reaching for the eternal (or beyond the edge of the page), and the line most common to English speech being blank verse. I don’t know how much I believe that, but it’s interesting. Some of my more private poems have longer lines, but perhaps they are reaching out for something beyond the page, such as “Hypoesthesia.” I do generally count my syllables and try to maintain some semblance of consistency, whatever the line length. Most of my poems are around a 10 syllable line, but I enjoy longer lines, too, generally letting the first couple lines fall where they will, creating a good first unit of meaning or line break, which determines the shape of the rest of the poem. My poems that go off-margin and tumble down the page usually have more space between lines and might approach a difficult topic from an altered angle, but it’s not a system I negotiate. It’s more of a feeling, and I’ve noticed this similarity between some of those poems. And the pacing of the poem is determined by its shape. The off-margin poems use all that space to also create pauses in a halting kind of tone. Sometimes I use a large space in a regular, on-margin poem, to indicate a halting quality as the speaker articulates an emotionally difficult conclusion.

The concept of a poem being space, or the page being space, is so interesting, not only because a stanza is a room in Italian, but because a poem houses movement, sound, and speed, too. It’s a moving space with associational turns of mind, memory, image, and feeling, with the potential for new associations leaping between lines and across gutters.

**TF:** In your essay “Erasure as Reclamation” (2012), you define erasure as when “the poet enters a dialogue with the original text, "erasing" or crossing out some parts of it, while highlighting other parts as an act of resistance.” Can you explain your thinking about poetry representing this concept of reclaiming embodiment?

**LCL:** Erasure is a process of uncovering and revealing (or sharpening) an alternate text, whereas my poems that move around off-margin are originally crafted that way to convey mood and pace. With regard to a medical test result or article, it’s satisfying to cross out and “correct” the
original text’s dry misunderstanding of what it’s like to live in a body that doesn’t fit the norm. Medicine tries to correct our bodies, and through erasure a poet can correct their correction.

However, one could apply the concept of erasure to the prose fragments throughout Veil and Burn. They were originally part of longer lyric essays. I physically cut out the images, scenes, or paragraphs and taped them to sheets of paper, and then edited down, distilling the language and emotion, honing the voice of these fragments. In some prose fragments, I put scenes from different moments right next to each other, to intensify the interplay between them, as in [Mosaic Fragment] (the clinical experience of taking a color blindness test juxtaposed with viewing a Paul Klee painting at a museum) and [Fragment Dissected and Sewn] (dissecting kidneys in college interrupted by moments from a future episode of urinary urgency). Through the associative links between italicized and non-italicized text, I hope to create some friction and energy, as well as windows through which a reader can enter a different physical experience through other experiences s/he may have shared, such as friendship or dissection in school. Through these methods, I am re-visiting and reframing my own work by rearranging and editing.

In general, I find both poetry and lyric prose tremendous vehicles to reclaim and re/present embodiment. There are certain experiences which may be more emotionally fraught, such as vision loss, urinary incontinence, and memory loss, that at the time I was writing Veil and Burn, seemed too emotional or potentially sensational or maudlin for me to address in poetry. There is only one poem (in lines) that contemplates the process of Optic Neuritis, “Retrobulbar.” I felt more comfortable conveying vision loss and treatment in prose. Similarly, I find art or graphic memoir to be another language through which to convey other experiences that elude voice in my writing. I have since been able to address cognitive challenges and memory loss in poetry. It took a poem in rhyming couplets (“Upon Reading the Radiologist’s Report”) to take me there, and then visiting Jerome Rothenberg’s Technicians of the Sacred (2017) to investigate indigenous forms I could employ to express gaps in memory—which I tried
but ultimately returned to the off-margin airiness and halting voice alive in a lot of my poems, and I made “Burn Fragment.”

**TF:** Are there any particular philosophers, disability studies theorists or perception phenomenologists who have consciously influenced your work; and how have they influenced your thinking?

**LCL:** I am not sure how well this might answer your question. I read Susan Sontag’s *Illness and Metaphor* (1978) as an undergraduate, and I developed a contentious relationship with that book for many years, my multi-colored margin notes disagreeing with the text and with each other. I felt that metaphor played a vital role in conveying physical experience or biology. I didn’t yet understand the deeply embedded cultural uses of metaphor to demonize and mythologize illness and disability. I also didn’t yet understand that metaphor itself cannot be fully trusted to adequately convey experience. And we know her metaphor of illness as a kingdom, which is interesting in that it becomes a space that isolates individuals.

I enjoyed Wittgenstein’s *Philosophical Investigations* (1953), and I think Elaine Scarry is a sort of inheritor of his language game on our inability to comprehend one another’s pain. Scarry explores the alienation of pain (which I think holds for any somatic experience) in *The Body in Pain* (1985), which I relied on heavily for some of my academic work in graduate school. Our library had very few disability studies texts, but I was drawn—and still am—to the amazing work of Rosemarie Garland-Thomson. I also found some guidance in Irving Zola and Susan Wendell, but otherwise, when attempting to formulate my own theory of disability performance for scholarly work in graduate school, I found myself also turning to Gayatri Chakravorti Spivak. The idea that certain alien experiences could never be understood by the mainstream makes me think of temporarily non-disabled people’s perceptions of disability; they don’t want to listen or think differently, so communication of physical sensation is nearly impossible (which brings us back to Wittgenstein and Scarry). But of course my creative work
insists that it must be possible, and I try, hoping for a reader who will absorb the language and
dwell in the poems. I think Barthes is brilliant, and I am fascinated by Gaston Bachelard’s *The
Poetics of Space* (1994). I’m also very interested in Sunyaura Taylor’s work uniting animal
studies with disability studies. One element of DS that I find very compelling is the way that
theorists arrive at observations often through biographical experience, which brings theory into
the body and into felt experience, a more private sphere.

**TF:** In one of your online blog posts “Gaining Access” (2014) you state “What is inaccessible to
most readers offers me access to the world of words, to my world, where poetic lines serve as a
form of automatic doors, or elevators, or accessible parking spaces, ramps, lowered countertops.”
Can you expand on how you envision your work engaging with this opening up of the
relationship between poetry, the body and its representation on the space on the page?

**LCL:** Aside from the literal access poetry has provided for me and my particular MS-related
visual and cognitive challenges, I feel that poetry itself offers an immediacy of feeling—physical
sensation and emotion—something akin to Wordsworth’s spots of time, that can provide
glimpses of experience linked associatively, gleaning an empathetic response from the reader.
I’ve structured a Medical Humanities course, Lyric Medicine, around this idea in conjunction
with notions of nonlinear approaches to somatic experience. A couple years ago I was invited,
along with poet Jillian Weise, by scholar Harold Braswell to be part of his panel at a bioethics
conference. His idea was that disability poetry can serve as the bridge between bioethics and
disability studies, which makes a lot of sense. And with that, it’s easy to imagine the role of
empathy for a reader extending to the medical professional.

It is my hope that readers of my own work would get as close to literally feeling and
inhabiting the body’s movements and sensations in my poetry and prose. As *Veil and Burn* was
originally my doctoral dissertation, I can offer the observation of poet Kimiko Hahn, who was on
my dissertation committee. She said that the poems reminded her of Japanese dance instruction,
where the instructor physically positions the dancer’s body. She felt herself being moved in this way, which is what I hope for: a sense that the poems could make the reader feel an inkling of what it’s like to live in this body and help them develop awareness of their own physicality and the subjectivity of the bodies around them. I have heard from some readers, though, a distancing objectification of the speaker in my poetry, the reader unable to cross the line of gender or physical ability to inhabit something different.

**TF:** As you are aware, nearly thirty years ago, the Americans with Disabilities Act (ADA) was introduced. In your blog post “Gaining Access” you also go on to state: “Normal” is shifting. It’s been a long time coming.” Do you feel you have achieved or set about representing this shift in societal representation of embodiment through your poetry?

**LCL:** Oh goodness. I don’t know if I have achieved it, but if you look over the preceding answers, I think you’ll find ways that I hope to represent the validity and importance of the disabled body and the primacy of disabled experience. I think books like Beauty Is a Verb (2011) and the New York Times op-ed Disability series, which will soon be available as an anthology entitled About Us (2019), are evidence that some progress is being made, but it’s slow. Part of the reason for the slow movement of disability rights, I think, is due to ableism rooted in narratives of disability as tragedy, or narratives of overcoming, rather than forms defying narrative and claiming disability as a unique and beautiful state of being.
Appendix 4: Daniel Sluman Interview

TF: Given that the Atos poetry online anthology was compiled as a response to specific changes in British welfare policies, has that online group now disbanded? Did the group evolve? Are there similar issues still in play?

DS: Yes, the group came about as a reaction to the Conservative benefit changes in 2013. Sophie Mayer, Madelyn Burnhops and myself put out a call for submissions from disabled, D/deaf, and chronically ill poets for work that could act as a protest against the Fit-To-Work culture, that we could collate in one place online. We chose a website to keep these poems as we could all edit it, and it was accessible and free. I think we were all surprised at the influx of work we received, and we managed to bring together a lot of wonderful poems that came at a time when protest against the Tories felt like it was really gaining momentum. After a while the project quite naturally ran its course; all three of us had our own health to look after and separate projects to complete, and none of the FTW blog was funded or supported in any way by any external organisations. The policies of the Conservatives are much more severe now than they were back in 2013, and there is still a real need for more disability poetry to be made accessible, and I really do hope others can make similar projects to FTW: Poets Against Atos.

TF: Did all the Atos “Fit to Work” poems from the group get put into the Stairs and Whispers anthology? Were there any copyright/editorial conflict issues?

DS: After the success of FTW I had a conversation about creating a disability poetry anthology with Jane Commane at Nine Arches Press, and a little while later we had the green-light to make this book. I co-edited the anthology with Khairani Barokka and Sandra Alland, and Madelyn Burnhope also co-edited with us for a large portion of the development stage and helped us immeasurably, so there was this common strand of Madelyn and I moving from the FTW blog to Stairs and Whispers. By the time we actually got to the stage of collating poems for the book we
had received a whole batch of new work, and apart from a few pieces (including “Shove ten pounds of sugar…”) from FTW, it was completely different. As far as I can recall there weren’t any copyright issues and I was lucky enough to work with extremely gifted co-editors, and we all respected each other’s point of view enough to talk through each poem we received and make group decisions on what we wanted included.

**TF:** I love your poem “Shove Ten Pounds of Sugar in a Seven-Pound Bag (A Manifesto for Disability Poetry).” Can you tell us anything about what your thinking was for this poem? Why, for example, you selected the bag of “sugar” motif?

**DS:** One of the driving ideas behind this poem is that there is an otherworldly kind of magic that happens when able-bodied people are forced to pay witness to disability and its metaphorical power, as well as the ways it pierces and transgresses the ideologies they’ve ascribed to, often subconsciously. In this poem I write about being an amputee, that “i have an absence/ where my left leg should be” and that this absence “will be more powerful/ than if my leg was there,” and what I’m saying is that this process of normalisation and aspiration to a kind of bodily performance (the hours in the gym, the size of your chest, the length of your hair, the symmetry of your face) that most able-bodied people feel the need to engage with, which on many levels works to stigmatise and further disenfranchise disabled people, is actually less powerful than the mechanism of disability it is warring against. Some of the power of seeing my absent left leg is initially a form of novelty, but this hole in reality that you see “forces you to project/ your own emotional/ intellectual self” within it. What I mean by that, is that what you’ve been taught, or told, and what you believe (even subconsciously) about disability and embodiment, will be forced to come to the surface of your mind when you see my amputation. A lot of people won’t want to confront their thoughts about these things and so there is a real power of transmutation in people being confronted with images of disability and “deformity.”
When an amputee walks towards an abled person it can bring their pre-existing ideologies about embodiment and wellness to the surface and create a dissonance that many find too difficult to fully confront. This is what brought about the metaphor at the centre of the poem; this is what shoving ten pounds of sugar in a seven-pound bag is like. It doesn’t work, it’s messy, it provides a semantic and emotional excess that can’t be accounted for and that hopefully leads people to investigate it further. The image of putting more sugar in a container than it can hold was the simplest and most universal way I could find to make this work. A further secondary reading could also be made about the type of pity and infantilization that is the heart of many people’s opinions towards disability, and the choice of “sugar”; something excessively sweet, and potentially damaging,

**TF:** In “Shove Ten Pounds of Sugar in a Seven-Pound Bag (A Manifesto for Disability Poetry)” you refer to the “the shape of my body exists within space / there are gaps & absences / within & around my body.” I am wondering if you could say more about how you feel your poetry offers us a medium to explore ideas on representing the spaces “within & and around” body boundaries.

**DS:** The physical absences and gaps of my body, from the very cathartic lack of a leg, to the gaps in my hip muscles due to underuse, or the absences of matter in my spinal vertebrae that cause me pain, are for me, both physical and semantic at all times. My poetry and my poetics come from a practice that is very much focused on my life as a disabled person, and the experiences I encounter. These include chronic pain, the side effects of powerful medications, as well as the intersection of my disabled body with my wife’s. Because of this, my poetry is all I can do to give the reader the opportunity to understand how different the disabled experience is from a non-disabled one, and how social narratives often deny the disabled body the freedom we all deserve. The spaces within and around my body, my experience, and my mind, are imprinted the best I can in poetry for somebody else to understand.
TF: Do you still feel there is an “absence” of recognition about the reality of your lived experience? What are your pet hates about how others/society perceive or respond to your particular disability?

DS: Absolutely. There is not only a real lack of knowledge about the types of lives disabled people like myself live, but there is also a lack of desire to understand these lives. Representation of our lives seems to only exist in these two polar-opposites; that of a person who is bed-bound, without any real “adult-life” and the relationships, friendships, and careers that is implied by that, and the “striver” on the opposite end that does all the things able-bodied people do, seemingly through the power of willpower and “positive attitude” alone. The reality is that my lived experience is complex, messy, and falls through a number of privileges and disadvantages that throw up the kind of mirror to most people’s lives that they don’t want to look at.

With regards to my particular disability, the highly visible nature of my hip-level amputation produces a similar set of behaviours formed around pity or disgust. I’ve had many hands pressed on my shoulder with pity, and many people have told me I’m “brave,” but I’ve also had many people unable to hide their terror at seeing what they would consider my deformity, and I even once had somebody perform a prayer as I passed them in the street! This is why I refer to my disability as a mirror in some poems; it really does reveal people’s unguarded opinions, anxieties, and fears to me in a way that makes them very vulnerable.

TF: Would you say that your more recent poems are driven by a similar political agency?

DS: The current collection of poems I’m writing are all written from the day-to-day life of being disabled and living with a disabled partner, so yes, they are all political in a very personal way. Overtly political poems can exist on a real knife-edge between success and failure and can so easily sound smug or glib, so I decided to write only about the things that happen to my wife and I. I’m hoping that by showing the reality of being disabled in the UK at the current time it will be
enough to have an effect on people and cause them to question the government practices that define the parameters disabled people live within.

TF: Are there any particular poets, philosophers, disability studies theorists or perception phenomenologists etc. who have consciously influenced your work; and how might they have influenced your thinking/poetic style?

DS: The Disability Studies Reader edited by Lennard Davis, is a book of essays I come back to again and again, full of circled quotes, and important points marked with sloppy inked asterisks. That book introduced me to some of the best contemporary thinkers in disability studies, and taught me a whole genre of knowledge against the grain of the ideologies I have been taught as a child. The book still seems as exciting, revolutionary, and esoteric now as it did when I first opened it.

Mitchell and Snyder, Tom Shakespeare, Robert McRuer, and Susan Wendell are just a few of the names whose work influenced me from that book, and pushed me to find their work elsewhere, with McRuer’s *Crip Times* being particularly engaging. A lot of these names have influenced my general knowledge about disability in a sociological context, and how aspects like stigma and *othering* work within it. More specifically within poetry, Petra Kuppers, and poet-critics like Sheila Black and Jennifer Bartlett have influenced the ways I think about disability and poetry together. Because this is such a new emerging area of theory, a lot of the more influential theorists for me before that were from the periods of structuralism and new criticism. Roman Jakobsen and his work on defamiliarization is especially a big influence for how I think about words and how poetry works in the reader’s mind.

TF: What poetic techniques do you consciously employ to convey re-imagineings of the visibility of your disability experience? Can you elaborate on your choice of imagery and/or use of spatial motifs in general?
The majority of techniques I employ are chosen because they support the need for confessionalism, and usually revolve around contrasting “poetic” imagery with quite simple and conversational language that builds together towards some resolution. I love the magical realism of poets like James Dickey, and that motivates me to find unique and new ways of entering and framing poems whilst keeping the content personal. One of the richest techniques I’ve developed for exploring the disability experience is the use of medical language within new and usually unrelated contexts. The medical gaze is so inextricably linked with the disability experience that anything that works to invert or transgress this connection produces exciting new possibilities.

Image is very important to me within poetry, as I believe this is the sense we are most overexposed to in contemporary culture, which in itself produces exciting possibilities to create new meanings. Space is of great interest to me both within the content of poetry, but also in terms of spatial aesthetics and poetics. The work of Larry Eigner in representing his daily life and world through white space on the page is a massive inspiration to me, and I have been using space rather than punctuation in my poetry for as long as I can remember. Using space in the way poems are written and read is one of the many ways we can encode the disability experience in poetry, and I’m highly conscious of trying to represent this experience in white space myself. With regards to motifs, and especially in “shove ten pound of sugar in a seven-pound bag,” space is discussed in different ways to talk about the idea of embodiment and the implicit leakiness of disabled bodies.

Could you perhaps also comment on how the typography and verse form of your poetry is used to replicate the subjective negotiation of different types of real and imagined spaces and situational contexts?

Leading on from my last answer, space and spatial contexts in the page seem to provide a way of exploring disability that hopefully a lot of people will understand. Compared to an imaginary “ideal” body that we see everywhere around us in advertising, bodies affected by
physical disabilities often spill over or pull back space, as in the case of amputees, or people with conditions such as muscular dystrophy, or even elephantiasis. The differences and potential for variety in the way bodies inhabit spaces is something that I like to reflect in my verse, as I believe in art we are always to some degree replicating life. My motivation to reflect disabled bodies and lives in my work means opening up space more than most writers may think of doing, and utilising different areas on the page for words, rather than keeping everything indented left automatically. In some cases, there is not much I can say critically to give you a specific reasoning behind the choices I make, as a large amount of this is based on an instinct that I have been trying to hone for the last decade of writing

**TF:** How do you envision your work engaging in the opening up of the relationship between poetry, the body and its representation on the space on the page? Do you see any distinctions in the ability of prose and/or poems to achieve this?

**DS:** I hope that the way I utilise form over the body of the page does some work in disturbing norms and forces a questioning in the reader that might lead to thoughts about disability and bodily representation. The majority of my content is about being disabled now, in a period where stigma and access are still issues disabled people encounter every day. I’m by no means the only person writing this, but I really hope that this mixture of confessionalism and form help open up differing ideas about how bodies take up space in the world as well as the page.

Whilst I don’t read, write, and know enough about prose, I do know that poetry seems to be a great fit for exploring disability. Life is messy, complex, and full of ambiguities, and the potential in using a more expansive form in poetry means there is a lot of room to represent different forms of disability.

**TF:** You said once that your poems adopt a confessional tone when refashioning subjective experience. In what ways do you think your poems are also written to help us imagine future spaces by re-imagining new/ utopian spaces we might one day inhabit?
DS: A lot of that depends upon the reader. When a writer shows you a sub-optimal experience of a human being, one that is terrifying, painful, and consistently maintained through the implicit actions of society, your response as a reader and as part of that society, is usually to empathise, but the next step forward is where things become political. That is what I think of when you talk of imagining future spaces, whether utopian, or merely just less oppressing, for disabled body-minds. I like to push & pull the boundaries on what we define very neatly as body, and by doing that you naturally bring up ideas about spaces where all bodies are included and made allowances for.

The reader’s response need not be political with a capital P, but just by changing the reader’s understanding of disability we can make a real impact on the way the world makes space for us. This in itself can become a radical act, as the majority of people without disabilities will never deeply think about the structural inequalities that maintain the oppression of disabled people, and so, to change that would be incredibly powerful. I do have a realistic attitude about poetry and how the reader can be affected, but in just changing the way a reader engages with other disabled people they know that could be a subtle but powerful difference in some people’s quality of life. This is not why I write, but it is one of the biggest reasons why I believe in the value of writing.

TF: What project(s) are you working on at the moment in your poetry?

DS: My third collection of poetry is the main thing I’ve been writing since 2015; a book about being a disabled person living with another disabled person, and what that entails during a time of political austerity. I have also been writing a 400 odd page document of thoughts about writing and disability that is somewhere between a diary, journal (with pictures) and a manifesto or declaration of poetics. I have no idea if it will be something that could be put in a publishable form, or if anyone would want to read it, and it may be just for me, but it is most definitely
helping me work through each day with more intent towards exploring disability, collecting all the little thoughts that would otherwise slip through the net of brain fog.

**TF:** Is there anything about your own poetry/disability poetry that you have been interested in talking about but no one has asked?

**DS:** I’ve been very fortunate to have this conversation with you. Without questions asked of myself so many of these things I feel strongly about would become unsaid and lack any musculature, and surely disappear from my own thinking. I think a lot about what I am doing with regards to writing, but a lot of my own views, technically, politically, and creatively are all the more formed and defined because we’ve had this exchange, and I can only thank you for your curiosity.
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