

School of Media, Culture and Creative Arts

**‘And Besides: Autobiographical Essays on Parenting and Difference’
and
‘Representation, Counter-narrative and Culture in Parental Memoirs
about Autism’**

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signature:

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Abstract

This thesis comprises a creative work and an exegesis. Together, they explore a specific type of relational life writing, that of parents writing about their children with autism. I examine the narrative stances and strategies available to parental memoirists and how these can be used to represent the child in an ethical way, to create a narrative that counters more traditional views of disability and to engage with the cultural dimensions of autism.

The creative work, 'And Besides', is a series of connected autobiographical essays which explore my experience as mother of an autistic son. While each essay focuses on a single theme, the work as a whole interrogates notions of normalcy, difference and disability, and charts the growth of my own understanding of the idea of neurodiversity and how one might parent from this perspective.

The exegesis analyses five published parental autism memoirs and the narrative strategies used to represent the children, and disability, within these texts. I examine the narrative stance taken by the parent-narrators and the extent to which these memoirs can be read as counter-narratives. I argue that the most progressive memoirs are those where the parent takes a role as cross-cultural translator and embraces autistic values and culture, thus offering a vision of social change.

Parent narratives about their autistic children are one of the clearest examples of the dilemmas associated with representation and power inequality in relational life writing. Whilst my thesis has not resolved these dilemmas, it provides a contribution to the life writing and Disability Studies literature in its exploration of these issues through both scholarly and creative practice.

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And Besides:

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**Representation, Counter-narrative and Culture in Parental
Memoirs about Autism**

Introduction

At the end of *Autism and Representation*, Mark Osteen calls for the development of an ‘empathetic scholarship’ in research and writing about autism. This ‘convergence of the personal and professional’, of ‘experiential knowledge and scholarly rigour’ (297), is precisely the sort of scholarship that I am endeavouring to practise in this exegesis, informed as it is by my role as writer, scholar and mother of an autistic child.

My initial purpose in writing a life narrative about my experience of parenting was twofold: I wanted to understand more about what it meant to mother a child whose developmental path was so different from the typical one; and I wanted to convey to others my son’s personality, especially his complexity and his value. From the beginning I was clear that I wanted to contest what I believed to be the dominant popular and medical understandings of autism, challenging the notions that autism is a collection of deficits and that autistic people are inferior to non-autistic people.

In making the decision to write an autobiographical narrative about an autistic child, I recognised that I was giving myself a number of challenges. The first set of challenges was around the ethics of writing about a child who was vulnerable because of his age, his relationship to me and his disability. Linked to issues of privacy and his ownership of his own life and life-story, was the challenge of ethically representing another. As well as the representation of my son, I was aware of the complex ethics of representing autism and disability in general.

The second set of challenges was around the nature of autism itself, what might be described as the ‘unnarratability’ of autism, a neurological condition that is characterised in the medical literature by repetition, narrow interests, and lack of communication and interaction with others. Given the deep connection between the western tradition of autobiography and individual identity, autonomy and independence, writing autobiographically about a child with a developmental disability seems somewhat paradoxical. Indeed, the way that autism (as constructed in medical and psychological discourse) appears to contest the key constituents of life writing – identity, embodiment, agency, experience, memory (Smith and Watson) – was one of the reasons for my interest in writing autobiographically. I

wanted to explore these apparent contradictions, particularly around identity, narrative and autism.

My research focused on the narrative strategies parents use to write life narratives about their autistic children that address the twin challenges of ethical representation and narrativity. My research took me into the fields of life writing, especially scholarship on relational life narratives, and Disability Studies, particularly analyses of the representation of disabled people in literary and other texts. I also read published works of memoir about illness and disability, including parental memoirs about disabled children, especially autistic children. I was not expecting, and did not find, solutions to the dilemmas of this sort of life writing. However, my research identified a range of forms, narrative stances and representational strategies used by life writers, and some of these were useful in my own creative work.

Using the frames of both Disability Studies and life writing scholarship, this exegesis analyses five parental memoirs about autistic children, exploring the representation of the child, of autism and of disability, and the way the role of parent-author is negotiated within the text to create narrative drive and structure.

In Chapter 1, I delineate different paradigms for representing disability, provide a definition of counter-narrative and summarise the dominant cultural narratives about autism. I briefly explore the reasons why parents might write memoirs about their autistic children and the current literature on such memoirs. Chapter 2 analyses three parental memoirs about autistic children, exploring in particular the representation of the children and the extent to which the memoirs can be read as counter-narratives. I conclude that none of these books are totally successful as counter-narratives and that the role and stance of the parent-narrators were a key factor in this. The focus on the nuclear family in these memoirs enabled the writers to create narrative drive but failed to allow them to explore the wider social and cultural dimensions of autism and its construction and reception in the community.

In Chapter 3, I consider alternative ways to create narrative drive in life narratives about autism and unpack the relationship between narrative and personhood or value. I explore the anthropological concept of liminality and how it might apply to parents of autistic children and the role of parental memoirs in addressing marginalisation. Adopting a neurodiversity approach to autism, I liken parent-narrators to cross-cultural translators and identify some key components of

ethical cross-cultural translation. In Chapter 4, I analyse two parental memoirs as forms of cross-cultural translation and identify how this narratorial stance enhances the representation of both child and disability and allows the memoir to be read as a counter-narrative. In my Conclusion, I identify the form, narrative stance and strategies I used in my own creative work and the ways in which I attempted to address the challenges of ethical representation, creating narrative drive and producing a counter-narrative. I reflect on the way my creative work is a record of a journey and how, if I wrote it now at the end of my research, I would write something quite different.

The five parental memoirs that I have chosen for close analysis were published by commercial publishing houses between 1993 and 2008. Four are written by Americans and one by an Australian. Two are written by men and three by women.¹ At the time of writing them, none of the parents considered themselves autistic, though one parent (Paradiž) was later diagnosed with Asperger's Syndrome. The children described in these books would be described as more able, or less impaired, than many autistic children, as would my own son. There are parental memoirs about less able children (see for example Michael Blastland, Charlotte Moore and Kate Rankin) but I analyse books that feature children similar to my son because the challenges of representation are similar. For example, the children are all verbal, so how their words are incorporated into the text is crucial to the act of representation. The five memoirs I analyse demonstrate a range of positions, from accepting the medical model of autism (Maurice) to constructing a counter-narrative that embraces autistic culture (Paradiž).

In my use of language around autism and disability, I have been guided by the Disability Studies field and the writings of autistic people. I use the term autism, rather than autism spectrum disorder, partly for shorthand and partly in response to concern about the notion of autism as a 'disorder'.² In keeping with the disability

¹ I recognise that there is a difference in motherhood and fatherhood and in the memoirs written by women and men. Given the number of issues I wanted to discuss and the space constraints, I decided not to make gender a focus in this exegesis but to explore it in another paper (Robertson, *Sharing Stories*).

² The term Autism Spectrum Disorder is used to refer to a range of conditions, including autism, Asperger's Syndrome, Rett's Syndrome, and other pervasive developmental conditions. In relation to the term 'disorder', Wendy Lawson says: 'I do not experience my being autistic as being "disordered"'

rights movement, I distinguish between impairment, to mean a bodily or cognitive anomaly, and disability, to refer to the results of this impairment. When I use the term disabled person rather than person with a disability and autistic person rather than person with autism, I do so deliberately and in acknowledgement that being disabled or autistic may be an identity term. Following the lead of autistic writers such as Jim Sinclair, I have tended to use person second language, rather than ‘person with autism’. Being autistic may be an integral part of a person, not an add-on or something they have which could be removed or cured. I use the term neurotypical to refer to those who are presumed to be (or presume themselves to be) neurologically typical; in this case, I am generally using the term to refer to non-autistic people.³

I use the term memoir to describe the books I analyse in this exegesis because it reflects current terminology both in the publishing industry and in life writing scholarship. Smith and Watson, for example, say of memoir that ‘the term refers generally to life writing that takes a segment of a life, not its entirety, and [focuses] on interconnected experiences’ (274). They suggest the greater importance of intersubjectivity in memoir over autobiography, noting that ‘the memoir directs attention more toward the lives and actions of others than to the narrator’ (274). While other terms, such as auto/biography and somatography (Couser, *Signifying*), have been used to describe the narratives parents write about their disabled children, I have stayed with the more commonly used term of memoir.⁴

or “impaired”, so much as I experience it as being “dis-abled” in a world that doesn’t understand autism!’ (*Understanding* 12).

³ Other neurological differences which fall into the atypical category include bipolar disorder, schizophrenia and other mental health diagnoses.

⁴ In the end, I used the term ‘autobiographical essays’ rather than memoir in the title of my own creative work. This is partly because of my use of the personal essay form (which I discuss in the Conclusion to this exegesis), partly in recognition that the work is more about me than it is about my son, and partly to signal my suspicion of the predetermined redemptive narrative arc (Bradley) expected from commercial memoirs.

Chapter One: The Challenge of Ethical Representation

Ethical Representation

In his Introduction to the 2004 edited collection *The Ethics of Life Writing*, Paul John Eakin writes: ‘Meditating on the breakdown of narrative identity...has led me to think of ethics as the deep subject of autobiographical discourse’ (6). He is referring here to the argument made in his earlier books (Eakin, *How Our Lives, Touching*) and by other life writing scholars (such as Bruner and Parker) that society demands that we can articulate an ‘identity narrative’ in order to show that we have a working identity and are thus endowed with ‘personhood’ and valued as a human being (rather than merely a sentient being). In his book *How Our Lives Become Stories*, Eakin in fact discusses autism and suggests that, as a ‘limit case’,⁵ autism shows the adaptive importance of narrative identity and the exchange of narratives to social bonding and solidarity. He argues that to achieve a socially recognised identity, individuals need both to narrate their lives and display a certain repertoire of emotional affect (both of which appear lacking in some autistic people). The absence of these features, he argues, causes others to assume that ‘dysnarrativia’ demonstrates a damaged identity. Eakin is not claiming that people who can’t tell a life narrative necessarily have a damaged identity. Rather what this shows, he claims, is that we live in a culture that values narrative functions as ‘the signature of the real, of the normal’ (140).

The nexus of narrative identity, personhood and ethics goes to the heart of any discussion about parental autism memoirs, gesturing, as it does, to both the potential benefits and costs of such life narratives. Perhaps more than many other disabilities, autism triggers issues of narratability and personhood. This is partly because some autistic people are unable to communicate what we currently understand to be a narrative of identity,⁶ partly because of the role of repetition in autistic people’s lives,

⁵ The phrase ‘limit case’ comes from Sidonie Smith’s 1996 article ‘Taking it to a Limit One More Time: Autobiography and Autism’, discussed by Eakin in *How Our Lives Become Stories*.

⁶ I use the phrase ‘currently understand to be a narrative of identity’ to refer to spoken or written narratives that conform to either everyday or literary norms. Other possible ‘narratives’ might be

and partly because autism has been described in medical discourse in ways that appear to deny the humanity of autistic people. As I discuss below, almost all parents writing about autistic children address the issue of personhood or ‘being human’ in their memoirs. As a parent writing a memoir, and considering whether to pursue commercial publication of this memoir, I am aware that there can be a fine line between the attempt to create a narrative identity that confers personhood on a child through ethical representation and a narrative that stereotypes the child or turns the child into a representative of his or her disability.

The growing body of literature on the ethics of relational life writing addresses issues such as privacy and ownership, informed consent, ‘vulnerable subjects’ (Couser, *Vulnerable*), the privileged knowledge of parent-authors and the representation of the subject. In writing my own memoir, I had concerns about all of these issues and attempted to address them in various ways.⁷ For this exegesis, however, my primary focus is on the issue of the representation of the child and his or her disability in parental memoirs, an issue which intersects, at least to some extent, with all the other ethical issues noted.

To explore the representation of autistic children in parental memoirs, I consider what Couser (*Paradigms’ Cost*) calls the paradigms of disability expressed in the works. I analyse the discourses and rhetorics used in the works and the ways they

gestural or behavioural ones, which non-verbal autistic people can certainly display (see for example Amanda Baggs’ video ‘In My Language’). David Goode describes the use of non-symbolic, alingual communication by deaf-blind individuals, while Cynthia Lewiecki-Wilson discusses the ‘performative rhetoric of bodies that “speak” with/out language’ in the case of cognitively impaired people (157). Eakin’s point, however, is that we expect or demand coherent word-based narratives from each other.

⁷ For example: I obtained Ethics Approval from my University; I discussed ethics regularly with my supervisors; I undertook research into ethics and life writing and used the knowledge in my own creative work; I changed the names of all individuals in my work; I spoke to my son about my work so that he was informed at some level, even though I did not ask for his consent because I did not believe that would be fair or reasonable (given his age, his cognitive differences and his relationship to me); I asked my son’s father and several other family members to read my work and give me feedback on potential harm to my son and others; I tried to make clear that my work represented only my understanding of the situation and no one else’s; I included an essay called ‘Carving, Forging, Stealing’ on the ethics of writing about my son; I avoided writing about certain things that may later embarrass my son (such as toilet training) unless they were necessary to my work; my thesis will be embargoed from free electronic access; and I have so far only published my essays in academic or literary journals rather than seeking any commercial publication.

characterise the child in order to identify the extent to which a memoir can be read as a counter-narrative.

Couser's three key paradigms are the symbolic paradigm, the medical paradigm, and the social-cultural paradigm. In the symbolic paradigm, 'impairment serves as a trope for a moral or spiritual condition' (22). While disability is not always presented as negative, the symbolic paradigm 'always generalises, stereotypes, essentialises', erasing 'individual differences within the group', thus reducing individuals to a single impairment or trait (23). In the medical paradigm, impairment is viewed as a dysfunction or medical problem. The disability is seen to reside in the individual and medical technology is viewed as the way to change or normalise the individual to the extent that they can function within society. As Couser notes, one may accept the value of medical interventions in life without accepting the medical paradigm as an appropriate mode of representation of people with a disability. The third paradigm, the social-cultural paradigm, developed from the disability rights movement and is central to critical Disability Studies. In this paradigm, disability is a socio-cultural construction 'located at the interface of particular bodies with particular societies' (22). It includes a differentiation between impairment (the bodily anomaly) and disability (the social response to impairment), removing the medical paradigm's focus on the individual as the locus of disability. This paradigm acknowledges the part played by social and cultural norms in the construction of disability, and views accommodation of difference as equally or more important than the attempt to change or rehabilitate the individual with a disability.

Couser admits that 'this schema of three paradigms is somewhat simplistic as a tool for analysing representation' and that writers are likely to use more than one paradigm in their work (28). He also refers to the different strands of thinking which fall into the socio-cultural paradigm, some of which are exclusively social constructivist and some of which include biology or the body and psycho-emotional issues as part of the socio-cultural construction of disability. However, I believe his schema is useful in analysing the work of parents writing about autistic children because of the history of symbolic representations of autism (explored below) and the current and growing challenge to medical definitions of autism coming from autistic people and based on the social-cultural paradigm.

Disability Counter-narratives

The social-cultural paradigm encourages representations of disability that challenge stigma and marginalisation, and may result in a type of counter-narrative or counter-story, ‘that resists an oppressive identity and attempts to replace it with one that commands respect’ (H.L. Nelson 6). Counter-stories position themselves against master narratives and act to reduce the diminished moral agency of oppressed groups. Nelson describes master narratives as those narratives which reflect socially shared understandings; that is, she is referring to dominant cultural narratives rather than Lyotard’s notion of master narratives as a grand or meta-narrative (though the two have a close relationship). Harris, Carney and Fine describe master narratives as

the social narratives created in the interests of dominant classes as well as the institutions they embody. They contain seemingly unambiguous information about specific social/cultural philosophies of justice and social prescriptions for behaviour as well as cultural values and directions for moral evaluations. (8)

Andrews notes: ‘one of the key functions of master narratives is that they offer people a way of identifying what is assumed to be a normative experience’ (1). In other words, master narratives are official or hegemonic narratives internalised and reproduced in everyday life.

Counter-narratives, then, are those stories that offer resistance to dominant or official everyday narratives and question dominant assumptions.⁸ According to Nelson, they act to resist exploitation, marginalisation, powerlessness, cultural imperialism and violence, but they also exploit the power of narrative to represent the complexity of relations between dominance and resistance. As Harris, Carney and Fine argue, ‘Counter stories have the complexity of lived experience at their heart – they resist simplistic understandings in favour of complicated, morally ambiguous and sometimes messy analyses of privilege and domination’ (9). Counter-narratives are not simple acts of resistance, any more than master narratives are stable and unified. Just as master narratives are susceptible to fracture and subversion, counter-narratives may be both complicit and countering. This

⁸ I am using the terms counter-narrative and counter-story interchangeably here although others may distinguish between them.

complicity as well as the contesting aspect of counter-narratives can be seen in the parental memoirs I explore.

In *Narrative Prosthesis*, Mitchell and Synder argue that disability pervades literature as a stock feature of characterisation, an opportunistic metaphorical device and a plot foundation, whereby the disability represents a deviance or disruption that requires narrative repair. The disability, in effect, creates the need for narrative, which must then resolve the social/moral problem or breakdown. Lennard Davis notes that narratives involving disability, ‘always yearn for the cure, the neutralising of disability’ (*Bending Over* 99). In what he terms ‘the normalcy narrative’, the disabled character must either be normalised or removed.

For parents writing about their disabled children, the fact of disability (either the child’s impairment or the result of this impairment on the child’s life) is usually the major motivation for the life narrative. That is, disability is the disruption that requires narrative, if not narrative repair, and the family’s response to the disability becomes the plot of the memoir. There is a risk, then, that the parent falls into writing a normalcy narrative, one in which the impairment becomes a problem and must be neutralised through cure, death or some other narrative device.

Writing about disability as disruption and the need for narrative repair, Mitchell and Synder contrast popular narratives (both cinema and print) with literary narratives, arguing that, while popular narratives enact a cure or kill approach to the disabled protagonist, there is a slim tradition of literary counter-narratives that contest this manner of storytelling, using disability to develop social awareness. These counter-narratives take a progressive approach to disability and use strategies to represent it that are politically enabling, allowing disabled social agency and challenging the underlying master narratives about disability resulting from the medical model.

Over the past twenty years, the number of disability counter-narratives has grown significantly, with autobiographical writing by people with disabilities forming a large part of this growth. Writers such as Nancy Mairs, Simi Linton, Robert Murphy and Anne Finger have published autobiographical works which are clearly intended as counter-narratives. Autistic writers such as Donna Williams, Wendy Lawson, Tito Rajarshi Mukhopadhyay and Lucy Blackman have also published memoirs which can be read as counter-narratives, with many more autistic people writing or

performing online counter-narratives. There is also now a small body of counter-narrative literature written by non-autistic parents about their autistic children.⁹

While the majority of parental memoirs fall into the category of normalcy narratives, some are both complicit with and resistant to popular and medical narratives about autism. I shall briefly explore these dominant narratives before discussing three parental memoirs in detail.

Autism Narratives

One of the first books I read about autism when my son was diagnosed was *The Handbook of Autism: A Guide for Parents and Professionals* by Maureen Aarons and Tessa Gittens. The second edition of the book was published in 1999, the same year my son was born. On page 32, I read: ‘It seems likely that children with autism are born with the basic knowledge that they are members of the human race either absent or impaired.’ Leaving aside the issue of whether any children are born with such ‘knowledge’, this quote shocked me with its implication that autistic people are somehow not full members of the human race. However, I was soon to discover that this was not an unusual idea and that many works about autism, whether textbooks or books for the general reader, reflected this notion. Oliver Sacks, deeply sympathetic as he is to everyone he writes about, still questioned the humanity of autistic artist Stephen Wiltshire in saying: ‘Stephen’s drawings may never develop, may never add up to a major opus, an expression of a deep feeling or theory or view of the world. And he may never develop, or enter the full estate, the grandeur and misery, of being human, of man’ (*An Anthropologist* 232). Even writers like Peter Szatmari, who want to assert that autistic people are indeed human, may do so apologetically: ‘And the simple giving of gifts is surely one of the hallmarks of being truly human.’ (100).

These questions about ‘being human’ arise from the ‘triad of impairments’ seen to characterise autism and used for diagnostic purposes. Someone receiving an autism spectrum disorder diagnosis will have demonstrated: ‘qualitative impairments in reciprocal social interaction’, ‘qualitative impairments in communication’, and ‘restrictive, repetitive, and stereotyped patterns of behaviour, interests or activity’ (American Psychiatric Association). It appears that the failure to communicate and

⁹ For instance Ralph Savarese’s *Reasonable People*, James Wilson’s *Weather Reports from the Autism Front* and *Elijah’s Cup* by Valerie Paradiz.

interact socially with others demonstrated by some autistic people can trouble us so deeply that we question their humanity.¹⁰

To view this another way, the triad of impairments that define autism might be read as a manifesto of desirable behaviour (in reverse). For example, a ‘total lack of the development of spoken language’ (American Psychiatric Association) can be a self-evident example of deficit, or a statement about how important spoken language is in our culture. One could argue, then, that autism contests – or at least lays bare – some of the key values of our society: the desirability of certain types of social interaction, the importance of spoken language and conversation, acceptable forms of imagination, the relevance and importance of some activities over others.

Both Davis and Mitchell and Snyder argue, with different emphases, that the fascination with disability in cultural narratives is actually about creating and protecting the idea of normalcy. The examination of difference and disability, according to Davis, is ‘nothing less than a desperate attempt by people to consolidate their normality’ (*Bending Over* 117). The sick or disabled person acts to create knowledge about normalcy. Mitchell and Snyder argue that the reason disability erupts so often in US literature is that, like race, ‘disability represents a powerful, yet culturally un-integrated conflict within the national psyche. It is the site where the conflictual nature of our beliefs about “viable lives” gets acted out’ (178). I would argue that this is particularly the case with autism. Autism research has told us an enormous amount about non-autistic or neurotypical people.¹¹ And yet autism is still considered to be an ‘enigma’ (Frith) and autistic people to be puzzling or unknowable.

As many writers in Disability Studies have pointed out, normalcy is a construction dependent on its unequal opposite, abnormality or disability. They are unstable and relational terms but are often used in medical discourse as absolute categories. Douglas Biklen points out that most scientific accounts of autism treat it as a stable concept that is internal to the individual. He compares this with the view that autism is a concept ‘developed and applied’ (12), not natural or discovered, that

¹⁰ David Goode says that ‘to treat verbal communication as the basic vehicle for human understanding is to fall victim to what Merleau-Ponty called “the ruse of language”’ (88).

¹¹ To give just one example, research into autism has resulted in the development of the concept of ‘theory of mind’, a capacity which neurotypical people are said to demonstrate and autistic people said to lack (Baron-Cohen).

can be viewed as a set of qualities among many. This is not to deny the neurological and other differences between autistic and non-autistic people or to suggest that these differences don't result in disability. But it does question the idea that autism is a stable concept internal to an individual with a diagnosis. Foregrounding the constructed nature of autism and reflecting the social-cultural paradigm of disability, Biklen argues that 'people classified as autistic as well as those around them...have choices to make concerning which constructions to privilege' (65). The medical literature reflecting the medical paradigm of disability privileges constructions based on autism as a deficit or defect and this has shifted into popular and media discourse.

After undertaking a content analysis of the 1228 print media articles about autism published in the Australian print media between 1 January 2002 and 31 December 2005, Jones and Harwood note that 'autism as problem' was the most significant underlying message of the news reporting. They argue that media coverage of autistic people, especially children,

presents a dual stereotype: either uncontrollable, aggressive, and even violent, individuals who cause great stress to their families and carers or unhappy and often unloved and poorly treated (both by the system and by their families). Only in a very few cases were children, or adults, presented as having any positive characteristics – and these were consistent with the 'stereotype' of...the autistic savant who has exceptional talent in a particular area. (15)

They also note that 'references to the negative impact of autism on family members and family functioning were pervasive throughout many' of the articles, and that parents were generally portrayed as either 'stoic individuals who cope but are damaged and traumatised by the experience or as uncaring or incapable parents who harm or abandon their children' (15).

This representation of autistic people as either problematic or exceptional and their parents as either traumatised or abandoning is not confined to the Australian media, as Moody, Murray, Osteen and Waltz have shown. These powerful master narratives about autism and parenting, combined with the more sophisticated but reductive dominant narratives of medical discourse, suggest that to have an autistic child is a tragedy for a parent and that autistic people are of minimal value in society. The desire to counter these representations provides a strong incentive for parents in

particular to write experience-based life narratives about autism. One difficulty for a parent attempting to write a counter-narrative, however, is the strongly metaphorical constructions of autism in the dominant narratives and the way they act to embed the symbolic paradigm (together with the medical paradigm) into so much of the medical and popular discourse on autism.

Mitzi Waltz argues that there are a number of key metaphors that recur in narratives about autism. These include the 'empty fortress' notion, the changeling child, the feral or wild child, military metaphors, puzzle metaphors, and alien or stranger metaphors. The notion of 'the empty fortress' was used by Bruno Bettelheim as the title of his influential (and now discredited) 1967 book on autism. Sontag points out the long tradition of metaphorical thinking about the body as fortress and illness as invader. She says, 'modern medical thinking could be said to begin when the gross military metaphor becomes specific' (9), and illnesses are described as the alien 'other'. The more mysterious the illness or condition, the greater the metaphorising. According to Sontag, the effect of such military imagery is significant: 'It overmobilises, it overdescribes, and it powerfully contributes to the excommunicating and stigmatising of the ill' (94).

As Waltz points out, Bettelheim's fortress image contains within it many of the metaphors of autism since employed, including the idea of the emptiness, otherness and non-humanness of autistic people, the notion of the hidden 'real' self, and the notion of puzzle or enigma. She suggests that Bettelheim's empty fortress refers to the Germanic myth of Parsifal, holy fool turned knight, who searches for the Holy Grail:

If breaching the walls of the empty fortress to liberate the Holy Grail was Parsifal's quest, Bettelheim's use of the metaphor positions the therapist's quest as breaching the defenses of the autistic child to reveal his human self. By doing so, he declared that the 'problem' of autism lay within the child, who Bettelheim believed had built these barriers as a defense against abusive parenting. (*Metaphors of Autism* 3)

Waltz goes on to point out that alongside the metaphor of the imprisoned, hidden or invisible child, the rescuer motif supports a pervasive myth: that a 'normal' child is locked inside the autistic child, awaiting the heroic rescuer.

The notion of a military campaign to ‘unlock’ the autistic child was used in one of the earliest parental memoirs about autism, *The Siege* by Clara Claiborne Park, and continues to be used by groups such as *Autism Speaks*, a parent fundraising and medical research group. As more medical research has been undertaken, the puzzle metaphor has become more prominent. The Autism Association in Western Australia, as in many other places, uses a jigsaw puzzle as its logo.¹² Metaphors of changeling children, wildness or ferality are also common in narratives about autism, and as Waltz points out, they clearly render their subjects ‘as less than human’ (*Metaphors of Autism* 4) and ripe for medical or magical intervention.

These common metaphors all link Couser’s symbolic paradigm to his medical paradigm. In these metaphors, autism acts both as a dysfunction (the medical paradigm) and as a moral or spiritual trope for either child or mother (the symbolic paradigm). The idea that the autistic child is locked inside him or herself, ready to be rescued by a heroic doctor or therapist allows the two paradigms to merge in the act of rescue or normalisation through medical intervention. This conjunction of symbolic and medical paradigms is strengthened, I believe, because of what Waltz describes as ‘the echoes of the Parsifal legend’ and the notions of innocence and purity associated with Parsifal. The figure of the innocent but unwell child is a hugely powerful symbol, one which goes against all our expectations and beliefs and which requires a narrative – if not real life – response.

As Waltz notes, many autistic people (for example, Amanda Baggs, Michelle Dawson and Jim Sinclair) have interrogated these metaphors and argued against them. This, however, does not appear to have lessened the hold that these metaphors have in public life. Nor has it reduced the role of autism as an important bulwark for normalcy. If, as Davis suggests, the examination of disability is ‘a desperate attempt by people to consolidate their normality’ (*Bending Over* 117), then the creation of autism metaphors is surely a desperate attempt to patrol the borders of normality.

This role of autism as an extreme border for normality makes it perfect material for the writer wanting to explore human nature. As Polly Morrice says:

It’s easy to see autism’s appeal to storytellers. Even mildly autistic people have problems communicating and understanding social

¹² In *Elijah’s Cup*, these puzzle logos are mockingly described by an autistic artist as ‘Little Puzzle Head’ (Paradiž, *Elijah’s Cup* 210).

behaviour; what's more, these difficulties remain tantalisingly unexplained in an era when medical advances have demystified so many other ailments. We now know too much about, say, cholesterol, for a writer to portray heart disease as metaphorically as Ford Madox Ford did almost a century ago in *The Good Soldier*. But writers can still turn to autism when they're looking for an ailment that can drive a plot and convey what English teachers once called 'layers of meaning'.
(n.p.)

While many novelists have used autism in this way, it provides a real challenge to the life writer whose story is about autism but who wants to contest the symbolic and medical paradigms and write a counter-narrative using the social-cultural paradigm.

Parental Autism Memoirs

There is now a growing body of published narratives about autism written by parents. Park's 1967 book *The Siege* is generally considered to be the first such memoir, with a flood of parental narratives occurring over the past two decades. In 2005, Waltz noted that 'there are over fifty published accounts of autism by parents' (*Reading Case Studies* 428) and the number would be greater now.¹³

Neurodiversity.com lists ninety-two books by parents on autism and the UK-based specialist publisher Jessica Kingsley includes seventeen parent memoirs in their 2009-2010 catalogue.¹⁴

Alongside these works is a small body of scholarship critiquing these memoirs.¹⁵ Waltz divides parent narratives into 'illness narratives' and accounts of using particular types of therapeutic interventions, that is 'advocacy or instructional literature' (*Reading Case Studies* 428). She argues that parental memoirs about autistic children express an ambivalent position between the expected medical paradigm of 'loss' and 'stress' in relation to a disability diagnosis and an activist position on disability. She says, 'There is a juxtaposition between acceptance of

¹³ If there are around one hundred professionally published parent memoirs (in English), then there are also likely to be many self-published works and, of course, works in other languages, some of which are starting to be translated into English (for example *Dear Gabriel* by Halfdan Freihow).

¹⁴ Both accessed 4 October 2010.

¹⁵ See Debra Cumberland, Chris Foss, James Fisher, Mark Osteen, Sheryl Stevenson and Mitzi Waltz (*Reading Case Studies*).

these mainstream [medicalised] discourses and...their subversion through the seemingly straightforward description of personal experiences' (433). She also notes that many parent narratives have the stigmatisation of parental identities 'at their core, placing the person with autism in a secondary position within the narrative' (428).

Mark Osteen attempts to map the emerging subgenre of parents writing about autistic children in his Introduction to *Autism and Representation*. He identifies five common aspects in these works. Firstly, each memoir attempts to mediate between autism as it is lived and as it can be narrated, finding a strategy to 'depict stasis or constant interruption' (19). This is the challenge I identified as creating narrativity. Secondly, the narratives attempt to explore the effects of the diagnostic label and whether it is liberating or imprisoning. Thirdly, each narrative depicts the parent's method of dealing with the feelings associated with the diagnosis, feelings Osteen summarises as 'shock, grief, rage and guilt' (19). Fourthly, Osteen notes the parents' desire to negotiate a path between the idea that autism is a 'terrible demon' and the sense that it 'may also be a gift' (19). I consider that in many parental memoirs these three aspects – the diagnostic label, the parents' feelings and the demon versus gift issue – are linked to the challenge of representation and the role taken by the parent-narrator. Finally, Osteen notes that in writing memoir parents often use their own experiences as opportunities to generalise about education, medical treatment or therapy for autistic children, becoming advocates for certain types of intervention. Again, in my view this advocacy role arises when the parent-narrator takes a particular narrative stance, as I discuss in the memoirs analysed below.

While some parent-authors explain in their memoirs why they have chosen to write and publish their works, others do not. It is clear that some parents are writing to challenge stereotypes about autism or particular medical views (for example, Park wrote *The Siege* to contest Bettelheim's views on the aetiology of autism) and some are writing to promulgate a therapeutic approach (for example, *Let Me Hear Your Voice* by Maurice strongly promotes Applied Behavioural Analysis). Alternatively, for some parents the impulse to write about their lives may be generated by the desire to know their child better. The sense that their autistic child is profoundly different from them, together with the nature of the condition (limited or unusual language use, difficulty with social communication and unusual and repetitive interests or

activities), means that parents of autistic children may, in fact, feel they hardly understand their child. By bestowing narrativity on their child, they may also be reclaiming their own relationship with him or her. Other parents (for example Barbara LaSalle and Michael Whelan) note their desire to share their journey and provide support for other parents.

However, the reasons for writing a parental memoir may not necessarily result in a memoir that enacts the author's agenda unequivocally. The demands of the autobiographical form itself (and the book publishing and marketing industries) may exert a subtle pressure on the writer to make his or her child 'more interesting' and thus a suitable subject for autobiography. There may be a demand that the child is recognisably autistic, that is, conforms to the prevailing stereotypes. There may also be a demand for change or development, in the sense that the child at the end of the narrative is in some way different from the child at the start. The available cultural stories about autism may constrain the author from implementing his or her desired approach. The dominant narratives of autism as problem and family tragedy and the marketplace requirement for illness and disability stories to be uplifting and redemptive may combine to create a version of Davis' normalcy narrative, where disability is neutralised through the work of the narrative.

This normalcy narrative is similar to Arthur Frank's 'restitution narrative'. Writing about illness narratives, Frank (*Wounded*) identifies three different types of narratives: the restitution narrative, the chaos narrative and the quest narrative. While autism is not an illness, Frank's discussion is relevant in relation to the parent's experience. While many disabilities are diagnosed at or soon after birth, autism is not diagnosed until the child is between eighteen and thirty months old.¹⁶ For the parent, the experience of the diagnosis at this stage is, in some ways, similar to the onset of a chronic illness. The kind of disruption that the parent experiences may mimic some of the disruptions of sudden and serious illness: a shocking diagnosis, pain (mental rather than physical), a complete change of lifestyle, an immersion in the health/disability system, and the demand to find a new role or identity as parent. Frank describes how the experience of serious illness can result in the loss of both the 'destination' and the 'map' that previously guided the individual. For a parent whose child has been diagnosed with a life-long condition like autism,

¹⁶ In the case of Asperger's Syndrome, the diagnosis can occur much later, even in adulthood.

the destination of raising the child and the map or set of assumptions that guided the parent are suddenly called into question.

As Frank notes, for many people experiencing such disruption, constructing a narrative – whether internal, spoken or written – is a way to reclaim the experience in terms that make sense to the individual. Telling self-stories is a way to both retrieve an identity from the narrative wreckage of illness and to refuse to surrender to the colonising effects of medicine. According to Frank, a restitution narrative is one in which the protagonist was healthy, becomes ill and then well again. It counters illness and disability with cure. In this way, it is similar to Davis' normalcy narrative, as the illness or disability is removed. Frank argues that the restitution narrative is the master narrative through which our culture addresses illness. 'The restitution story, whether told by television commercials, sociology or medicine, is the culturally preferred narrative' (83).¹⁷ He also notes that in such a narrative, the self is dissociated from the body, the cure is commodified and the body is either a disciplined one (that is, compliant to the cure) or a mirroring body, identifying with previous or new images of wellness. In this narrative, the (passive) heroism of the ill person is in being a good patient, while the physician takes the role of active heroism. As I argue below, these ideas are productive when applied to parental memoirs.

The restitution narrative is limited, obviously, by the fact that not all ill people become well. In the case of autism, most parents recognise that their autistic children will not cease to be autistic. As Frank says, 'When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real' (94). The chaos narrative is the opposite of the restitution narrative, because its plot 'imagines life never getting better' (95). The chaos narrative is a 'mute' illness story, a story beyond speech. The chaos story can't be told so much as lived, because once it is told it becomes retrospective. The voice of chaos, however, can be identified, Frank describing it as 'an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself' (98). This description is actually very like the speech of some autistic people (the muteness of other autistic people may also contain aspects of the chaos

¹⁷ Both restitution and 'recovery' narratives can be viewed as forms of the conversion narrative, which Eakin (*Touching*) says is the oldest continuous tradition of autobiographical writing.

story). Certainly, my son and I have had ‘conversations’ over the years that appeared to reflect aspects of this anti-narrative, atemporality and a sense on my part that he was not aware of the separation between our two consciousnesses. According to Frank, the body telling chaos stories is controlled by contingency and unpredictability and represents a threat to others in its vulnerability. As I argue below, the chaos narrative may erupt in parental memoirs without the author’s intent.

Frank’s third type of narrative, the quest narrative, meets suffering and illness head on and seeks to use it. Illness or disability becomes ‘the occasion of a journey that becomes a quest’ (115), out of which something will be gained. Restitution stories are about medical intervention; chaos stories remain mostly within; but quest stories are the ill person’s own story that can be shared. Frank describes the quest narrative in the form of a hero’s journey, moving from the departure (the first sign of illness) to the initiation (the trials of illness) to the return with a gift of experience or insight. He depicts the body of the quest story as communicative. It is a body that accepts contingency but aims to share the gift of the journey with others. We can see this desire to share the results of experience in many parental memoirs; indeed it appears to provide the rationale for some parents to write about their children.

Frank says, ‘The quest narrative recognises ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice’ (134). In this way, the quest narrative is one that can, but may not always, act as a counter-narrative to contest the symbolic and medical paradigms of disability.

In Chapter 2, I start my analysis of texts with a work that conforms to the normalcy narrative: a classic autism ‘recovery’ or restitution memoir that has been influential among parents and therapists working with autistic children. I then discuss two more complex and ambiguous narratives where the authors appear to be working to challenge this restitution narrative.

Chapter Two: From Restitution to Quest

‘Unmitigated Pain’

Anne-Marie had now become a source of unmitigated pain. She was going so fast into some shadowy space, and I didn’t know how to reach her. As each day passed she seemed to fade more and more into herself, into a private dreamy world where she wandered alone. We were losing her. (Maurice 44)

This is how Catherine Maurice describes her daughter, Anne-Marie, at one year old in her memoir *Let Me Hear Your Voice: A Family’s Triumph Over Autism*. First published in 1993, the book tells the story of how two of Maurice’s children were diagnosed with autism (Anne-Marie first and then Michel) and her five year journey to move them into ‘recovery’¹⁸ through the use of intensive behavioural therapy.

Maurice describes how Anne-Marie began to ‘slip quietly away from us’ (4) and was ‘wandering into darkness’ (20). She notes, ‘I was in a race against time, and either I found something that truly helped or I had lost Anne-Marie forever’ (57). As her daughter exhibits more ‘autistic mannerisms’, Maurice increasingly feels she is ‘losing’ her daughter. Autism itself begins to have a character in this book, being described as a ‘black cave’ (57), a ‘jagged hole’ (21), a prison, a concept that ‘gave meaning to the phrase “death in life”’ (57). Maurice often uses religious imagery (she is a committed Catholic), contrasting God with ‘this evil’, autism (60).

Maurice sets up a dichotomy between the ‘autistic self’ and Anne-Marie’s ‘real self’, working to ‘bend, break and ravish her autistic self’ in order to get to the true ‘Anne-Marie spirit’ (81). Using the classic fortress and siege metaphors, Maurice determines to ‘besiege’ her daughter, destroy the autistic self and drag her ‘into the human condition’ (81).

¹⁸ The term ‘recovery’ is used by Maurice to refer to her interpretation that her children are no longer autistic. I use the scare quotes to signify the dilemmas raised by a belief that autism is like an illness that one can recover from, rather than a neurological difference or a diagnosis given to people based on certain criteria.

In this way, Maurice establishes a symbolic equivalence between autism and death and between what she terms ‘recovery’ (the non-autistic self) and humanity. At one point Maurice writes, ‘Anne-Marie would be whole and normal. She would talk and smile and grow and love’ (67), thus suggesting that autistic children aren’t whole, don’t develop and can’t love properly. Like any mother, Maurice wants her daughter to love her and wants signs of this love. When she doesn’t receive these signs – smiles, eye contact, desire to interact – she conflates the lack of evidence of Anne-Marie’s love with a lack of love, again relying on the autistic self/real self dichotomy to understand this.

In fact, Maurice admits in her memoir that she is using these terms ‘autistic self’ and ‘real self’ in a symbolic way and that this approach can be questioned. She says that while she now (at the time of writing her memoir) disagrees with the notion that there is a normal child locked within an autistic shell, parents who are ‘fighting’ for their child need this fictional construct. And in many ways, her memoir relies on this, because without the notion that she is recovering her true daughter from the ravages of autism, the type of story she is writing would change completely.

By constructing this dichotomy of autism versus true self, of the lost child versus the recovered child, Maurice creates narrative tension and motivation. Her story becomes a classic restitution narrative where autism is seen solely as an assault on the normal order and the narrative arc entails a journey to return to the pre-disability order. Maurice’s underlying premise is that autism is the enemy which must be fought and vanquished so that the family can return to normal life. As with many restitution narratives written by parents, the struggle for restitution is performed by a number of heroic characters, including clinicians and parents. The child becomes the ground over which these characters act rather than a heroic character herself and the sign of success is that the child becomes like other children, what Maurice describes as ‘normal’.

Here is Frank’s dissociated and disciplined body: the child is made to comply with behavioural modification therapy and then to mirror the desired attributes of being well or ‘normal’. Maurice describes her therapist, Bridget, working with Anne-Marie (who is almost two years old):

As soon as Bridget placed Anne-Marie in the opposite chair the crying broke out in earnest. Anne-Marie tried to get out of the chair; Bridget

kept placing her firmly back in. She collapsed on the floor; Bridget picked her up and put her back in the chair. She tried to put her hands in front of her face; Bridget took them down and held them in her lap.

(87)

Maurice is devastated to watch her daughter like this but believes that this is the only way she can be helped. The therapy pays off. At the end of the book, Anne-Marie appears to be a happy six year old who meets all her developmental milestones and is shown asking her mother what infinity means. There is no question that Maurice is a devoted mother, motivated by love for her children. However, in this narrative, she enacts the role of saviour as well as narrator, leaving her children to be the passive recipients of her actions.¹⁹ The children are only given agency and value when they ‘recover’.

Maurice notes that the ‘black-and-white’ approach to ‘recovery/nonrecovery’ is probably no longer useful (302), however she never questions her primary assumption that ‘recovery’ is better than ‘nonrecovery’ or that a ‘normal child’ is preferable (for parents at least) to an autistic child. In this way, she views autism solely as a medical condition without any value, an individual deficit with no social or cultural dimension.

Maurice’s memoir reflects both symbolic and medical paradigms of disability (as described by Couser). In the symbolic paradigm, autism becomes the opposite of God, ‘the human condition’, and the loving family. The ‘triumph’ of the family over autism represented in the book means that Anne-Marie and Michel are ‘redeemed’ (290): ‘We walked through the valley of the shadow, and now we walk in light’ (291). Couser notes how the symbolic paradigm, as well as commonly presenting disability as negative, generalises and stereotypes, erasing individuality. Thus, all autistic children – and all aspects of autistic children – are represented by Maurice as damaged and barely human. This emerges in her characterisation of her children. Her descriptions of her children’s autistic behaviours are presented in general terms such as crying, twirling strings, grinding teeth and sitting in corners. Maurice adopts

¹⁹ In this Maurice may partly be acting in response to the ‘assumption of maternal omnipotence’ (Hillyer), where society places responsibility on mothers for all that happens to their children. As Hillyer and others have pointed out, this myth of the omnipotent mother is, paradoxically, even more likely to surround mothers of disabled children than non-disabled children.

medical language such as ‘stereotypical’ and ‘self-stimulatory’ to interpret this behaviour. Maurice is clear about her aims – to make her children ‘whole and normal’ (67) – and her narrative never questions this goal, its underlying values or how she understands normalcy and disability. Her children only start to become real to the reader near the end of the book when they begin to recover: she can’t capture the specifics of her children when they are autistic, only when they are ‘normal’.

Maurice’s construction of autism as evil/death and recovery as humanity feeds into the medical paradigm that views autism as deficit and normality as wholeness. While Maurice argues against certain medical views (for example, the psychodynamic approach to autism), she appears to accept the medical paradigm and to have no qualms about identifying the specific form of intervention that she believes ‘recovered’ her children from autism. In fact, her story of ‘recovering’ her children becomes a kind of advocacy for behavioural modification intervention, even to the extent of including an Afterword by Dr Ivar Lovaas, one of the key proponents of behaviour modification for autistic children. Maurice does admit that not all children ‘recover’ in the way her two did. This doesn’t change her approach; she still maintains the medical view of disability as a defect that should be righted. Those children who don’t ‘make progress’, as she puts it, are ‘still there, left behind’ (302). Her children have been rescued, but others are still ‘lost’. This reflects Frank’s comment that the restitution story is powerful when true but offers nothing when there is no cure. In this construction of parenting a child with autism, if your child doesn’t ‘recover’, then you are back in narrative wreckage without destination or map.

Let Me Hear Your Voice is a powerful book, partly because of the triumphal ending but also because Maurice uses language beautifully and expresses the full range of her emotions. Because her children are ‘recovered’, she may have felt freer to express herself than other parent-authors. She can express her full horror about her children’s behaviour because that behaviour changes.²⁰ Couser (*Conflicting Paradigms*) has identified four rhetorical approaches taken by conventional disability life narratives: the rhetoric of triumph, of horror, of spiritual compensation and of

²⁰ It should be noted that she protected her children by publishing under a pseudonym and changing her children’s names.

nostalgia.²¹ He contrasts these with the rhetoric of emancipation, which he says works to contest received notions of disability, resulting in a disability counter-narrative. Interestingly, Maurice uses all four of Couser's rhetorical approaches in her memoir. In the early stages, horror predominates, together with nostalgia for the pre-autistic child Anne-Marie once was. As the therapy is successful, the rhetoric of triumph dominates, as signalled in the book's subtitle. In many disability life narratives, spirituality is offered as a compensation for disability. In this book, Maurice's religious beliefs support her in her battle against disability. By linking autism and evil, she adds spiritual weight to her family's struggles. Because of this, at the end of the book when she asserts the 'fundamental holiness of all children' (291), it is an assertion that is unlikely to resonate with all parents of autistic children. Couser suggests that 'the conventional rhetorics for representing disability in autobiography do tend to...reinforce its stigma' (89) and this is certainly the case in *Let Me Hear Your Voice*. Maurice's adoption of the symbolic and medical paradigms of disability, her use of conventional disability rhetoric and her creation of a restitution narrative reflect a limited and limiting view of autism and of disability in general. She is less writing her children than righting them.

'Normal people'

Maybe we could go to the bush and hide from the gaze of all those strangers who stared at Charlie's strange behaviours when we were out in public. We could become virtual hermits somewhere remote; maybe my family could be 'normal' if I took them somewhere far away from 'normal' people. (Whelan 30)

These are the thoughts that Michael Whelan reports feeling soon after his son's diagnosis in his memoir *The Other Country: A Father's Journey with Autism*, published in 2008. As its subtitle suggests, Whelan's book is primarily about his own journey as father to a son diagnosed with autism. Whelan begins the book

²¹ These rhetorical positions are similar to the oft-quoted visual rhetorics noted by Rosemarie Garland-Thompson (*Seeing the Disabled*). She identifies four different rhetorical stances: the exotic (where the disabled are presented as alien, sensationalised or eroticised); the wondrous (where the disabled are presented as exceptional); the sentimental (the sympathetic victim); and the realist (which minimises distance and difference). She argues that only the realist stance can convey the lived experience of disability in a way that allows for agency and emancipation.

several days before Charlie's birth, presumably in order to establish his expectations about fatherhood, but the narrative skips two years within the first twenty pages to focus on the moment of Charlie's diagnosis. The narrative then covers in detail the family's attempts to understand the diagnosis, establish a home-based behaviour modification program, explore alternative treatments such as dietary intervention, auditory integration and secretin injections, find suitable schooling for him and, perhaps most prominently, accept his diagnosis and what it means for the family. In the final chapter, Charlie is seven, although the book's Epilogue shows us a snapshot of Charlie at age twelve.

The primary metaphor used in this book is the notion of the 'other country' of 'difference and disability' (216). Whelan introduces this metaphor by referring to a well-known article (which Whelan describes as a poem) called 'Welcome to Holland' by Emily Perl Kingsley. This short article likens having a disabled child to booking a holiday to Italy and then, when you arrive at your destination, finding you are in Holland after all. It describes the loss experienced by those who didn't get to Italy but also the different pleasures and 'special' attributes of Holland. Whelan notes that this captured his sentiments, speaking to him in a way the clinical literature failed to, and says that he and his wife, Helen, both stuck a copy on the wall near their computers. He also notes that Kingsley was writing about having a child with Down Syndrome and that another parent of an autistic child wrote a follow up poem in response called 'Welcome to Beirut!', suggesting that 'the terror of a war-torn city was a more fitting allegory for life as a parent of an autistic child' (38). Whelan doesn't comment on the Beirut connection, leaving the reader unclear about what he thinks about likening parenting an autistic child to living in a war-torn city.

Some twenty pages later, Whelan describes enrolling Charlie in an autism intervention program and notes, 'Our visa to the other country of "families with disabled children" was now formally stamped. It was time to be fully introduced to an imperfect world, the one that mirrors the one we used to know' (54). Although he suggests by implication that the world he 'used to know' was perfect, in fact he has already made it clear in the first chapter of his book that he and Helen were finding life with two young children (their second son, Thomas, was born when Charlie was eighteen months old) exhausting and challenging and were both taking anti-

depressants prior to Charlie's diagnosis. The perfect world is therefore more of an imagined previous world than a real one.

Whelan refers to this 'other country' of disability twice more in the text. When Charlie is around four or five, Whelan describes having dinner with friends and realising that, for the first time, he has accepted the reality that Charlie is autistic and might not 'recover' or return to 'normal'. For the first time, he acknowledges to himself that the family,

might never return to the place we'd come from. It was as though the prophecy in Emily Perl Kingsley's poem 'Welcome to Holland' had come true. I had finally looked around and discovered that this strange and achingly different country I had arrived in wasn't that bad after all. (176)

Although Whelan appears here to be moving from what he terms 'denial' to 'acceptance', in fact only one paragraph later he notes that over the last six months 'the landscape had changed slowly and imperceptibly toward a new vista, a new country' (176). In this newly-emerging country, Charlie is starting to speak, can toilet himself, read from a book, ride a bicycle and even look at his parents. Whelan says,

This new country was a refracted image of something like the world we used to live in: familiar, but different; terrifying but beautiful; tragic, but full of moments of joy...I didn't need or have to leave this other country. I could stay here and have a life that was loving, rewarding and, perhaps, even joyful. (176-7)

While Whelan is suggesting here that he has finally come to terms with difference and disability and can begin to see it as something closer to normal life – refracted now rather than mirror image – he is doing so only because his son Charlie is starting to meet (late) some of the expected milestones of typically developing children. The family isn't 'normal' but he suggests that someone passing by would think 'we mightn't seem all that different either' (176). That is, he can accept being in the other country only because it is starting to look a lot more like normalcy. A page later, he questions himself: is the family looking 'normal' to him only because his expectations have changed? Has Charlie really made significant progress or does he, Whelan, just want to believe that? His answer appears to come a few months

later, when Charlie is accepted into a mainstream school and a family routine ‘started to emerge that began to feel tantalisingly close to what it must be like to be a normal family’ (186). Here, Whelan approaches the notion that ‘normality’ is constructed but then dismisses this and falls back into treating ‘normality’ as a self-evident and positive reality.

In the book’s final chapter, Whelan again approaches the notion of the other country with ambivalence and contradiction. He compares his family’s journey with the ‘triumphant hymns of recovery in popular parental autobiographies’ and says that, while these journeys provided them with hope, their own family

hadn’t retraced the steps of any of these heroic journeys. While Charlie was a loving, expressive and beautiful child, his problems with language and social interaction meant there were still considerable hurdles to be faced. (216)

He goes on to say that ‘the other country of difference and disability that we had inhabited for the past four years’ gave him a new perspective and offered some unexpected riches, but that his family would now be ‘departing from it’ (216). It’s not clear here whether Whelan means that his family is departing from the ‘other country of difference and disability’ because Charlie is no longer so very different, or because they don’t consider him disabled anymore, or because they no longer identify with the group of families they knew when they were intensely involved in autism advocacy and the search for the best treatments. Later, he says of his wife and himself, ‘For years we had come to define ourselves as passionate healers, but that mantle has now passed on to the next group of families whose child has just been diagnosed’ (217), suggesting that he and Helen no longer identify with the disabled community. He goes on to end the chapter with, ‘We’re in a different place. A new country’ (217).

Whelan’s ‘other country’, then, is not the other country of autism or an alternative way of thinking or living, an autistic culture. His ‘other country’ is the place where families of disabled people live, the marginal world of the least powerful, least enfranchised people in our society. Whelan seems to accept that this marginal life is inevitable for disabled people, even at times seeming to welcome the hidden nature of this world, as I argue below.

Even though he uses the metaphor of another country in his discussion of autism, Whelan does not reflect the symbolic paradigm of disability with this metaphor. Unlike Maurice's use of metaphor, Whelan never presents autism or disability as a moral or spiritual trope. His book seems to reflect the medical paradigm, albeit with some reservations. In this the book exemplifies Waltz's (*Reading Case Studies*) comment that parental memoirs include both an acceptance and a subversion of medical discourse.

The interesting thing about Whelan's narrative is the way he identifies the genre of the popular autism 'recovery' narrative (such as *Let Me Hear Your Voice*) and its heroic parent/therapist and claims that this does not match his experience, and yet his narrative mimics many aspects of these recovery narratives. For example, for over eighty percent of the book's pages, Whelan describes himself as fighting Charlie's autism, noting his desire for miracle cures, his 'almost Biblical' hope (44) and his desire to 'land a punch on autism' (120). While some of his stories of 'miracle cures' (like getting a dog, which they kept for only three days) are described with irony, the irony refers mainly to the unrealistic nature of the intervention, and not necessarily to the idea of a cure or treatment that will lead to either 'recovery' or a reduction in Charlie's less socially acceptable behaviours. He undercuts his own heroic status whilst still representing himself and Helen as dedicated parents searching obsessively for a cure and working obsessively on behaviour modification and other interventions, so that they become, in a sense, flawed but heroic anti-heroes.

Whelan sets up his own idealistic expectations in the first chapter (even using the phrase, 'It would all be perfect' (4)), in order to give the reader the full irony and pain of his experiences when everything starts to go wrong, in retrospect laughing at himself with the reader. However, when things do 'go wrong' and get out of control, there is no indication that Whelan is rethinking his sense of normal life to recognise that difference and disability is a normal part of life. He appears to accept a conventional notion of normalcy, one which defines itself in opposition to disability. Whelan describes disability as 'an enemy intruder' (91), he assumes that grief is the main feeling parents will feel when their child is diagnosed with autism (130, 134), and he works very hard to try to make their family look like a 'normal family' (134, 212). Even though he mocks his own desire to 'parade his normalcy' (152),

Whelan's narrative stance suggests that he is mocking his parental pride over a small milestone rather than questioning his own views on normalcy. His great fear is that Charlie will be permanently dependent on others, saying that, 'If things had turned out that way for Charlie, I think it would have been almost too much for me to bear' (149), once again valuing normalcy and independence over difference and interdependence.²²

Whelan's metaphor of the other country and his inability to reconceptualise normalcy and disability run counter to his desire to write a narrative that is more realistic than the 'recovery' narratives he refers to in the text. He identifies the master narrative, tries to counter it through personal experience and yet ends up with a narrative as complicit as it is challenging.

He tries to avoid the rhetorics of horror and triumph that he identifies in popular recovery narratives, and succeeds on the whole (with perhaps one or two exceptions). He also avoids the rhetorics of spiritual compensation and of nostalgia. Occasionally he presents disabled people in sentimental ways, for example saying about some children with physical disabilities that, 'these angels with their twisted bodies writhing on sheepskin in the speckled sunlight were the most innocent and vulnerable creatures on earth' (35). Although he refers to Charlie's abilities, he does so in terms that are realistic and not part of the savant stereotype or as a compensation factor. In fact, Whelan is alert to the tendency towards freakery, describing his discomfort about aspects of behavioural rewards that 'had the smear of the vaudeville animal stage act' (104) and describing how he and Helen were so happy about Charlie's interest in the calendar that they celebrated with the 'shameless carnival of party tricks that we asked Charlie to perform every time a visitor was in the house' (191).

Perhaps the attempt to avoid sentimentalising or exoticising Charlie has led to Charlie's relative absence as a character in the text. Although so much of the story centres around Charlie's autism and his parents' attempt to 'find relief' (that is, ameliorate his autistic behaviours), we see and hear very little of Charlie himself. There are almost no scenes of domestic chaos in this book, unlike most other narratives about autistic children: no tantruming, no aggression, no running away

²² Whelan perhaps also finds it impossible to conceive of dependency and full personhood as compatible.

from caregivers, no anxiety attacks. Just occasionally Charlie is seen in action, 'slowly spinning in the corner of the lounge room' (39) or playing with his toys at night (112) or collecting objects as part of what his parents call a 'tribute alphabet shrine' (131-2). As the behavioural modification program begins to change Charlie's behaviours, though, he comes more alive in the text through descriptions of his play and laughter, his ability to sit at a desk and learn for ten minutes and his memorising of calendars. Describing his epiphany over dinner that the 'other country' wasn't as bad as he thought, Whelan notes about Charlie that 'the door of personality was now ajar' (175), and it is from this point onwards that Charlie begins to have a slightly larger presence in the text. Whether Whelan's failure to describe the younger Charlie reflects his desire to protect his son's privacy, the resistance of autism to narrative order, or his refusal to revisit and record painful memories, for the reader the result is the same: we never really get to know or care very much about Charlie. In this way, Whelan replicates the marginality of disabled people in our society, failing to create a sense of his son's personhood through detailed person- and experience-centred writing.

Further, Whelan's many references to shame, the unkind gaze of others and his desire to hide his son, reinforce the sense that autistic Charlie is unacceptable, even though this is clearly not what Whelan is attempting to express. References within the text to shame are very often linked to the gaze of others and to Whelan's desire to hide away. For example, he discusses moving out of the city to 'shield Charlie from the gaze of the unaffected' (30), the hidden school that allowed children to 'exhibit their varying degrees of difference away from the gaze of the local suburb' (56), his hurt when family members 'stared quizzically at Charlie's obsessive behaviour' (131), and his reluctance to socialise with other people in case Charlie's behaviour causes embarrassment. Whelan is obviously ambivalent about the relationship of shame to disability. He describes the Autism Association of Queensland's bus as 'some kind of shameful public herding' which signposts disabled children to be 'on display' for the gaze of the community (60) but never questions himself about why he assumes a bus full of autistic children (as opposed to 'normal' children) should be a matter of shame or be gazed at by others. While recognising that people with disabilities have often been subject to the gaze of non-disabled people and made to feel inferior and that many disabled people have felt shame as a result, Whelan never

unpicks how it is that he himself feels ashamed of his son's disability, regardless of whether the disability is signposted or not. From the evidence of the narrative at least, his own internalised shame appears to create more discomfort than any external shaming by others.²³

This contagious shame indicates the profundity of Whelan's pain and confusion, as do his references to his changed career goals, sense of meaning in life and the many traffic accidents he reports in his narrative. Describing how his concern for his son resulted in other things losing their meaning, Whelan notes that his loss of faith in his career 'was deepened each morning as I sat at the breakfast table with Charlie, trying to teach him to use a spoon, say my name, or learn to hug me' (73). The first of a series of six traffic accidents occurs when Whelan is stressed about work. Other accidents occur at other times of distress, each one being reported in a single sentence such as, 'Later, on my way home, I ran the car into the back of a nice lady's ageing Toyota' (135). One day he experiences an anxiety attack at work: 'Terror seemed to cut me to shreds, and the sense of dislocation that I'd felt between trying to reconcile "me at home" with "me at work" completely shattered' (122). He is unable to understand how parents of other autistic children focus on their careers, unless it is to use the career as 'a personal refuge from the reality of autism' (157). Eventually, Whelan leaves his job as a university music lecturer and becomes primary carer for his sons and Helen takes on full time work running her own business. This appears to address some of Whelan's identity issues and in 2004 in 'the warm glow of summer' (218), he decides to write a book about his journey with Charlie in the hope that his story may be useful to others. He notes that during the weeks he wrote the section on toilet training, he 'ran into the back of a white Holden Astra' and hopes that this signals the end of his motoring accidents (218).

Perhaps because of his own trajectory or his own views of what being a father means, Whelan doesn't seem able to imagine that one can be a loving parent of an autistic child and also pursue a career with interest and pleasure. The notion that he has to be two different people at work and at home only seems to arise for Whelan after Charlie's diagnosis of autism, suggesting that his inability to 'reconcile' the two selves is partly the result of his desire to protect himself and his son from the

²³ It is possible that Whelan's shame is partly about masculinity and his sense that he may have fathered a son who will never become an independent and autonomous male.

possibly judgemental views of others. His return to the home could be read as the desire to hide himself, acquiescing in the connection between disability, shame and institutionalisation. However, by writing his book, he returns once more to the external world and opens himself and his family to the gaze of the reading public. Once again, Whelan's ambiguous stance allows the reader to make different and even contradictory meanings of his text.

It is tempting to read Whelan's car accidents as an eruption of Frank's chaos narrative within a text that is predominantly a quest narrative. Whelan's book is intended, I think, as a quest narrative, the primary quest being Whelan's desire to understand and help his son and to rebuild his sense of self and fatherhood in the context of his son's diagnosis. The book is structured in the form of the hero's journey, with the diagnosis as the departure point, the many trials of parenting an autistic child comprising an initiation into the 'other country of disability and difference', and the memoir itself being the boon or gift that can be communicated to other parents on the hero's return.

The chaos narrative is, of course, mute or a voice unsequenced, immediate, atemporal and unselfconscious. We get a tiny glimpse of this in *The Other Country*, for example when Charlie says, 'Delete this to the old friends!' to express his dislike of an activity, conflating computer speak with the idea of passing old toys to friends (179). Because the chaos narrative is anti-narrative, it can't be woven into a book as willed craft; it can only erupt. Whelan's car accidents may be a form of chaos eruption but after a time they feel contrived, a sort of joke or planned objective correlative for Whelan's stress. Perhaps the real voice of chaos here *is* mute. Perhaps the chaos is the unresolved tension between what appear to be Whelan's intentions – to avoid the normalcy narrative and to de-stigmatise autism – and how the text resists such a reading, turning itself from counter-narrative to conventional narrative.

'I Couldn't See'

I couldn't see Ben. I couldn't find him through the lens I was looking through. And through my tears, I knew that to find him, to see him, to have him the way I needed to...I'd have to take off the lenses I'd been wearing. I'd have to wipe them clean. (LaSalle 264)

The parental quest is also a strong feature of Barbara LaSalle's book *Finding Ben: A Mother's Journey Through the Maze of Asperger's*. LaSalle's memoir, published in 2003 when her son was thirty-four years old and incorporating short contributions by him, is the story of LaSalle's journey towards 'finding' – that is, accepting – her son. This quest is signalled at the start of the book, not only in the author's Preface, but also in the book's epigraphs, one of which is about 'necessary losses' and the other about forgiving and loving people 'even if they have hurt you and let you down by not being perfect' (Kushner quoted in LaSalle iv). In a shocking Prologue, LaSalle paints her son as irredeemably 'other' and herself as an unnatural mother for her reactions to him. Ben is thirty-three and LaSalle is helping him with his shopping:

Thirty years of advising, commenting, suggesting. What *hasn't* been said in that much time? It's enough for both of us. I'm fed up with trying to change my son. I'm tired of how it feels to look at him and see layers of fat, to listen to him and hear a constant low-grade wheeze, to flinch at his flat feet, at the fixed, unchanging expression on his face, at his glazed, vacant eyes. I'm tired of trying to get a straight answer from a crooked person, even though that crooked person is my son. (1-2)

She goes on to say,

Ben is as different, as unblended, as *other* as I seek to be normal, an irony that does not elude me. Rather it haunts, punishes, taunts me. But what it does to Ben is worse. Because – despite his Asperger's Syndrome; his obesity; his chronic asthma; his Crohn's disease; his cortisone-damaged organs, bones and glands; his destroyed and unforgiving metabolism that will not yield an ounce of fat – he knows.

My son is aware that the last time I wanted to introduce him [to a friend] was when he was four. When I was still proud of him. (2-3)

LaSalle deliberately harnesses the symbolic paradigm to describe her son in pejorative terms that highlight his medical conditions and his difference from the idealised American young man. By distancing herself from him, labelling him as 'crooked' and 'other', and using language that links disability with the monstrous, the incompetent and even the immoral (crooked), LaSalle is establishing the beginning point of her quest. Her use of the rhetoric of horror is intentional. At the

end of the book, she once again goes shopping for Ben and delivers the food to his apartment, but this time, she stops in her task of putting away the food and turns to her son, 'I look at Ben and I see my son. He is beautiful in his green T-shirt. He is beautiful in his slippers. He is beautiful in his own smile' (270). In her Afterword she says that she has now 'found' Ben and loves and accepts him as he is. She forgives herself for her previous blindness to his value because she realises that she was 'only a mother suffering from a disappointment I had refused to come to terms with' (271).

In this way, LaSalle establishes the primary metaphor in her book as a search for her son, her subtitle describing Asperger's Syndrome as a 'maze'. Although her journey as mother has been over thirty years, the journey of the quest has actually been the time it has taken her to write her book. Both LaSalle and Ben describe the process of writing this book as one of the key reasons for LaSalle's change of heart and their improved relationship. In an epigraph to the final chapter, Ben says, 'Here's the big secret: I never changed. I'm still the person I was when I was little. The world just caught up to me' (263). It's hard to escape the conclusion that when he says 'world', he actually means his mother.

LaSalle's image of the lost child in a maze in fact subverts the traditional metaphor for autism, in the sense that the reuniting of mother and lost son occurs not through the son's 'recovery' but through the mother's re-education. He doesn't learn to be visible; she learns to see. Instead of the usual description of an autistic child as silent, lost or stolen away, Ben is described as a powerful, large and, at times, very verbally astute child and then adult. The 'maze of Asperger's' is not the conventional puzzle of autism that must be medically solved in order to return the autistic child to normal life, but rather an alternative way of living and thinking that neurotypical people must learn to decipher.

In parental memoirs about autism, the moment of diagnosis often marks the point at which the book turns towards a restitution or recovery narrative as the parents desperately try to 'cure' or 'treat' their autistic child. This is not the case with *Finding Ben*. Ben is twenty-three when he is finally diagnosed with an autism spectrum disorder. LaSalle says that she has spent over half her life asking what was wrong with her child and now she had the answer she 'felt bereft': 'Ben was the same – with or without a label. He had the same problems...And what about me?

Was I any different now? Had Ben's diagnosis changed me?' (244). She then goes on to say, 'I had arrived at the finish line, but I wasn't holding the prize. Ben was the prize, and I wasn't holding him' (245). The diagnosis of Asperger's Syndrome helps both Ben and his mother understand that Ben's difficulties stem from a neurological cause (rather than simply being willed behaviour) and therefore helps Ben feel less self-hatred and LaSalle judge him less harshly. The diagnosis also marks the point when LaSalle recognises that *she* has to change, not Ben. The chapter that follows is titled 'Living under Ben's Skin'. LaSalle notes that during their collaboration on writing this book, she asked Ben again what it was like living under his skin. She then reproduces Ben's answer, which makes up all but the initial paragraph of the two page chapter.

The final two chapters and Afterword cover LaSalle's change in attitude after Ben tells her she is 'addicted' to changing him (253). She diagnoses herself with 'Disappointed Mother Syndrome' (254) and volunteers to visit Jack, a 'man-riddle' (255) with language-impairment due to a brain aneurysm. LaSalle's conversations with Jack help her realise she must change her thinking, get over her disappointment in Ben and accept him for how he is, not try to change him – all the things that Ben, in fact, has been telling her. In other words, Ben's diagnosis of Asperger's becomes the point at which his mother is able to achieve her quest, and it is Ben himself who first articulates both her problem and the solution. Instead of the usual pattern of parent trying to change autistic child, we have here the child trying to change his mother. Ben's moral agency is given full expression in this quest narrative, countering the reductive stories of medical discourse.

In keeping with these reversals of metaphor and turning point is the approach to the characters of Ben and his mother in the book. Ben is the most realised character in the text whereas LaSalle comes across as obsessive and single-minded, unable to look beyond the railway tracks of her own obsession. This is particularly interesting in a book about someone with Asperger's Syndrome, because of the so-called obsessive behaviour that the literature claims characterises the condition. From as early as three years old, Ben is portrayed as having agency. When a nurse asks him to show her colleagues how he can read the newspaper at only three years old, Ben replies: 'I don't have to read it. I did that already this morning in my own newspaper. I'll just tell them what it says' (37). As well as illustrating Ben's

remarkable reading and language skills and his lack of understanding of other people's intentions (not realising that he is being asked to perform), this exchange demonstrates Ben's ability to make choices and follow his own logic. There are many similar descriptions throughout the book, as Ben chooses his own reality over LaSalle's (and society's) reality.

This is made explicit when LaSalle describes how Ben prefers looking at exhibits about San Francisco at the Museum of Science and Industry over being outside.

'Remember the San Francisco Bay diorama, Mommy? Everything – the bridges and ferries and ships, and even the cards – moved around, just like it was real. The water too. Even the sun moved across the sky like a real day.'

'But, Ben, we're in a real day now. This *is* a real day.' (31)

This clash of realities continues to grow as Ben ages, leaving LaSalle anxious that Ben is retreating into his 'own world' and then upset that Ben is telling what she calls lies and Ben's psychologist calls stories. Even as LaSalle points out that Ben is fantasising, and that she, his mother, doesn't accept him, she represents his reality as well as her own. As well as including descriptions of Ben and his dialogue, LaSalle has incorporated Ben's own words about the different periods of his life. Speaking about his fantasies, for example, Ben says,

My real life was never as good as what I could make up. Even as a little kid, I knew the life I wanted to live and the person I wanted to be would never happen. So I began telling stories out loud. Sort of like playing pretend, except only I knew it was a game. (85)

Here, LaSalle allows Ben to mediate between her own previous view of him as a 'liar' and the psychologist's opinion that Ben is 'imaginative' to show that, in fact, Ben's fantasies were the result of his failure to achieve the life he wanted.

Even when Ben is sexually abused at boarding school, is arrested for aggressive behaviour and held in prison in four-point restraints, LaSalle and Ben provide details of these experiences. By writing about such painful, and in some cases taboo, events, LaSalle provides the reader with the full range of emotional experiences that she and Ben have been through. Ben's representation thus changes from a man described as having a 'fixed, unchanging expression on his face' and 'glazed, vacant

eyes' (1) to one who has experienced the full gamut of feelings and can express these, saying, for example, about his time in prison:

I couldn't move. I couldn't move my head because it was locked in place. I didn't know if it was day or night. I began to scream at the top of my lungs. I screamed to God to let me die. I screamed and screamed and screamed. No one came to help me. I screamed some more. (177)

The use of Ben's own words in the text also demonstrates to the reader how Ben has grown over the years and the extent to which he has developed insight, not only into himself and his challenges, but also into his mother's personality. By the age of thirty-three, when his mother is writing the book, Ben has the insight to say:

I thought I could never tell the truth about any of this stuff. That if I did, it would kill me. But now I realise that that's not what would kill me. Spending the rest of my life hiding my true self – that's what would kill me. (243)

In the chronology of the book, this passage is presented before LaSalle's own discovery that she has spent thirty years trying to change Ben and refusing to accept her own disappointment and loss over the child he isn't. Although Ben tells his mother that she can't change him, he, in fact, does change or develop over time. In this way, the book reinforces both that having Asperger's Syndrome can't be 'cured' and is a legitimate way to live but also that a life with Asperger's does not doom you to remain forever the same, that people with Asperger's grow and develop just as neurotypical people do.

In these ways, LaSalle's representation of her son, and his own representation of himself as chosen for inclusion by LaSalle, contest the essentialising of the disabled individual. She eschews the stereotypes of savant versus helpless victim. She writes about Ben's unusual skills but does not portray him as exotic or wondrous and certainly doesn't sentimentalise him. She plays with the rhetorics of horror in order to make her point about her own inability to accept difference but never uses the rhetorics of triumph, nostalgia or spiritual compensation. She reverses the traditional metaphor of the maze or puzzle to show that it is the mother of the 'lost' child who must change in order to embrace or 'find' her child.

The medical paradigm is contested to the extent that LaSalle questions the desire to 'cure' or 'normalise' Ben and argues that it is society's views on difference – in

this case represented by LaSalle herself – that resulted in Ben’s most debilitating experiences. While gesturing here towards the social-cultural paradigm, LaSalle’s memoir doesn’t fully embrace it. As with *The Other Country*, a closer reading of the text uncovers contradictions that, to some extent, undercut the progressive nature of the text.

Like Whelan, LaSalle begins her book with the notion of a ‘perfect’ child and life, including also her fears about whether she would be a ‘perfect’ mother (7-8). She adopts the term ‘anomalies’ (used initially by her doctor) to refer to Ben’s physical differences from other babies. She then starts using the term ‘normal’ to describe textbook child development, thus conflating the notion of the ideal with ‘normal’ or ‘regular’ children. While recognising that Ben is very advanced in some areas (intellectually and verbally), she also sees his very limited development in other areas (social, physical, motor) and tries to work out what she calls ‘my most important question – the question of better or worse’ (43). The question of better or worse is LaSalle trying to work out whether having a child like Ben was better or worse than having a ‘normal’ child. This question then slides into a question about whether Ben is better or worse than other people.

Was he better because of what he *could* do, like read and talk and tell and know, or was he worse because of what he *couldn't* do, like have friends, make conversation, and play soccer? (231; emphasis in original)

LaSalle describes the ‘better or worse question’ as a stand-in for the question she is afraid to ask, which is what is wrong with her son. However, even after she starts asking doctors what is wrong with Ben (and gets various unsatisfactory and partial answers), she continues to frame the issue of Ben’s difference as a good versus bad issue. All LaSalle’s reflections on Ben are comparisons – he is always seen as either smarter or less competent than other children or young people. She assumes that there is a norm that exists and is represented by ‘regular’ children and constructs Ben as other to that norm. In this way, LaSalle, like Whelan, fails to deconstruct the normal/abnormal and non-disabled/disabled dichotomies.

LaSalle asks the better or worse question but it is clear that she would much rather that Ben were neither better nor worse but the same as this norm – what she describes as a ‘regular’ kid (27). The stigma of his difference affects her deeply: ‘If

my son didn't fit in, how would I? This was my worst nightmare.' (41) Ben, too, in his contributions to the book, reflects his own sense of shame about himself and his inability to achieve certain goals. In spite of the book's ending, where LaSalle notes that she now loves and accepts Ben 'as he is' and comments on his brilliance, courage and inspiring attitude, there is no attempt to consider how she or others might reconceive disability as difference or diversity rather than deficit.

Nor does LaSalle explore the wider cultural and medical issues that have helped to construct her own views on disability. She appears to write the book to indict herself for her inability to love and accept Ben unconditionally as well as to help other mothers with similar experiences. She takes all the blame for her culture's ableism onto herself and constructs the journey of healing as an individual quest, albeit one she can share in print with others. Given that the book shows Ben being treated harshly and unfairly by educational, judicial and medical institutions and individuals within these institutions, it is odd that LaSalle doesn't explore how the community in which she and Ben live has contributed to their experiences and attitudes.

This focus on the mother-son relationship and the construction and understanding of difference within that relationship results in Ben becoming a kind of 'yardstick' (Bérubé *Disability and Narrative*) for his mother's moral and social development. Although Ben is given his own voice and has a strong presence in *Finding Ben*, the trajectory of the story is that of his mother's journey to acceptance. Ben acts as a barometer for his mother's character, keeping the stigmatisation of disability as a moral issue within the family rather than a social and political community-wide issue. While *Finding Ben* reflects the growth of LaSalle's moral development, it does not reflect a larger social or political awareness. The book certainly provides an alternative to the normalcy narrative – Ben remains different and present right to the end. LaSalle's inclusion of Ben's own words and her representation of her own ableism act to 'recognise and respect autistic agency and authority' (Osteen 300). The power of this representation, though, is undercut by the way the narrative locates disability within the individual and fails to explore the role of society and culture in constructing disability to consolidate normalcy and place autism at the borderland. In Chapters 3 and 4 I identify possible ways to make this exploration.

Chapter Three: Narrative and Value

Creating Narrativity

One possible reason why the three narratives discussed above focus on disability within the nuclear family is to do with the difficulty of creating a dynamic narrative out of a story about autism. Maurice creates a plot through the family's fight against autism and her children's 'recovery'. Whelan's plot is around his own understanding and acceptance of Charlie's autism, as well as Charlie's trajectory through the immediate post-diagnosis period. LaSalle's plot is similar, in that although she describes events from thirty years of Ben's life, her plot is primarily her own journey towards accepting and valuing his difference. In the restitution story, cure provides the dynamic. In the quest story, the protagonist-parent's search provides the dynamic.

Describing living with serious illness as a life of perpetual or chronic interruption, Frank (*Wounded*) notes that temporality and memory are disrupted with the loss of the stable expectation of continuity between past, present and future. Narrative coherence – an ongoing and ever developing project for all of us – is harder when illness strikes. The same is true for disability. As Couser says,

part of the challenge of living with disability is precisely that it seems – sometimes, paradoxically, because of its 'stability' (stasis) – unpredictable, unnarratable, that is, inassimilable within the usual narrative formulas. (*Vulnerable* 150)

The unpredictability of life with a disabled child can be the result of living 'out of sync' with the expected developmental path as well as the involvement of a plethora of health practitioners and the emergence of unexpected health issues. In the case of autism, this is compounded by the 'desire for sameness' and continual repetitions of speech and action that autistic children demonstrate, which act to create a kind of looping effect of a life repeating itself rather than moving forwards.

This interrupted and repetitive life makes writing a narrative difficult. It is not so much that 'nothing happens' as that 'the same thing happens' again and again. I experienced some of this challenge when I read a first draft of one of my essays at a

writer's workshop. Several of my listeners commented that it was boring to hear my son repeating numbers all the time and that they probably wouldn't read on if I included too much repetition in the early parts of my essay. Where children are non-verbal or speak very little, the challenge is greater, in that the writer has to engage the reader with descriptions of actions that appear (to neurotypical readers) both repetitive and dull, for example, running sand through fingers or placing marbles in a row on the floor.

In other ways, too, the life of an autistic child can appear to be unchanging. For example, while a child will move to high school at the same chronological age as his peers, he may still exhibit many of the behaviours and interests of a young child. Kelly Harland, writing about her autistic son in *A Will of His Own*, captures this neatly in her chapter titled 'Potter vs Potter': while his peers are reading Harry Potter novels, her son Will is reading Beatrix Potter. This short chapter, in fact, is not about Will's reading interests so much as Harland's feelings of loss and marginalisation. The story shifts from son to mother in a pattern common to many parent narratives. The parent's journey provides the narrative drive to redress the seeming unnarratability of autism.

At a deeper level, there is a challenge in writing about autistic subjectivity if you are neurotypical. There have been debates in the literature, in fact, about whether autistic people experience a different type of subjectivity or selfhood, or even consciousness.²⁴ Certainly, many autistic people experience sensory integration dysfunction and perceive and interpret the world around them in ways that are different from neurotypical perceptions and interpretations.

The resistance of autism to narrative is compounded by the fact that some autistic people do not appear able to think in what Bruner (*Actual Minds*) identifies as the narrative mode (as opposed to the paradigmatic or logico-scientific mode of thought). According to Bruner, in order to think in a narrative mode, we need to construct two simultaneous but distinct landscapes, the landscape of action and the

²⁴ For example, see Smith and Eakin (*How Our Lives*). Patrick McDonagh makes an interesting suggestion that modernity and modernist notions of the self made possible the recognition of autism as a diagnostic category. He argues that the notion of autism arose partly as a response to anxiety about the 'isolated self bequeathed by modernism' (114) and the postmodern view of subjectivity as fragmented and destabilised. Autism, considered in this light, then becomes the opposite of what we assume to be the 'normal' self.

landscape of consciousness. It is the landscape of consciousness, which requires an understanding of human intentions, thoughts and feelings, that autistic people have trouble constructing. This may limit their ability to tell their everyday life story, the identity narrative that Eakin argues society demands of us all. Some autistic people may never emerge as Eakin's 'authorial self' who can re-tell events in different formats and for different audiences or purposes. Some may tell certain types of narrative but the episodes described may appear to be without the intentionality, causality and emotional layering that we normally expect from life stories.

Matthew Belmonte argues that when narrative organisation is impaired, autistic people may fall back on a 'simpler sort of associative learning', in which 'both essential and accidental correlations amongst perceptual inputs are learned equally strongly' (169).

This meticulous, systematic engineering approach to making sense of the world gives rise to a fundamental difference in the quality of autistic thought and the process by which autistic people establish abstract or global relationships: where others may begin with the concept and work down to the details, people with autism study each local detail in isolation, and work up through interactions to the concept. (170)²⁵

Belmonte's argument is that, for neurotypical people, narrative acts as a defence against the chaos and disorder of perceptual and sensory data and its impermanence and unpredictability, but that autistic people are unable to use this defence effectively because of their neural difference. Their alternative defence is what is described as 'repetitive and ritualised behaviour' and 'scripted interactions'.²⁶ A parent attempting to write about their autistic child may be attempting to translate some of these repetitive behaviours into a more socially acceptable and recognised form of narrative.

Given the vexed relationship of autism to narrative and subjectivity, one reason why a parent might write a memoir about their child with autism is the desire to 'narrativise' their child. Frank (*Moral Non-fiction*) describes life writing about

²⁵ This is an elaboration of the central coherence and executive function theories of autism (Frith).

²⁶ We might argue then that autistic people are creating their own 'narratives', but that these narratives are behavioural rather than linguistic.

illness and disability as ‘moral non-fiction’ because he believes it offers a form and forum for personal reflections on questions of value. He notes that the subgenre of parents writing about severely disabled children is animated by the tension between the institutional reductions of the child to his or her disability and a celebration of the child as a life. In this subgenre, parents are attempting to find the grounds for asserting the value of the child in a society in which many believe death is a better alternative than severe disability.

Frank argues that the justification for the value of their child requires these parents to make the child’s life narratable. He says, ‘this subgenre presents narratives about the limits of what is narratable: the writing is inherently reflexive, questioning what sort of a story it is, and even its own claim to be a story’ (184). This reflexivity, Frank argues, is moral work, because what is at stake is personhood and its entitlements. Frank’s argument here supports Eakin’s in that he agrees that narrative is seen to confer the value of personhood. In this case, however, Frank suggests that parents can bestow narrativity on their child by writing a family memoir; the child doesn’t have to narrate her own life to achieve social accountability.

Frank doesn’t raise the issue of the parents’ own personhood, but I suggest that many parents write about their disabled children partly to reclaim the child’s personhood and partly to reclaim their own parental personhood. Just as disabled children are considered lesser than non-disabled children, so, too, are their parents considered lesser than the parents of non-disabled children. Gail Landsman has argued that the ‘diminished personhood of the child with disabilities’ is linked to an experience of ‘diminished motherhood’ for the mother (135). Because a mother’s (and to a lesser extent, a father’s) moral value rests on her association with a valued or ‘perfect’ child, the parent of a disabled child is not seen as ‘morally equivalent’. To mother a child who is likely to remain dependent into adulthood is to be seen as a failure; ‘dependency and full personhood are conceptualised as incompatible’ (Landsman 149). Writing to assert the value of your child may also double as writing to assert your own value.

Return from Liminality

Mitchell and Snyder suggest that almost every culture views disability as a problem in need of a solution, situating ‘people with disabilities in a profoundly ambivalent

relationship to the cultures and stories they inhabit' (47). The parent of a disabled child will also be in a profoundly ambivalent relationship to their culture and stories. This marginality is well captured in the use of the anthropological concept of liminality to describe the place of people with disabilities in western culture.

Victor Turner, elaborating Arnold van Gennep's theory of liminality, describes the three phases within traditional rites of passage: the separation, liminal and aggregation phases. During the liminal period, the ritual subject is structurally (and sometimes physically) invisible in a condition of ambiguity and paradox. This period of dissolution and growth is also a time of reflection, when the ritual subject is witness to 'the basic assumptions of their culture' (Turner, *The Forest* 108). The liminal subject, being 'betwixt and between' is a non-person, structurally speaking, and therefore dangerous (hence the segregation). In the aggregation stage, the subject is reintegrated into a new stable role within the community, ending the period of liminal ambiguity and invisibility. In contemporary developed societies, Turner argues, what was in tribal societies a liminal transition phase, has become an institutionalised state of permanent seclusion (for example in some religious environments).

Robert Murphy and other scholars²⁷ have persuasively applied this anthropological concept to disabled people, arguing that they are placed by society into 'permanent liminality'. Murphy et al argue that the liminal model is the most useful framework through which to conceptualise the role of disabled people in contemporary life. Whereas sick people may transition back into a socially valued role (for example, leaving hospital and returning to work), people with a disability do not. Disabled people, Murphy et al argue, may be treated as non-persons, secluded from others and viewed as threatening or taboo. There are no real mechanisms for reincorporating disabled people into society except cure or death.

If disabled children reside in liminal space, then so too do their parents. A parent's subjectivity is shaped by the experiences of their disabled child; the social experiences of disability affect the parent as well as the child. The child's diagnosis of autism, for example, might constitute the parent's separation phase and the

²⁷ See Couser (*Vulnerable*), Willett and Deegan, Murphy and Murphy et al.

experience of parenting then changes as the family moves into the invisible and ambiguous place of the liminal.²⁸

Writing a parental memoir, then, may be a rite of passage for a parent, a way of reincorporating both themselves and their child back into society. Reading *Let Me Hear Your Voice* by Maurice in this light suggests another reason for her link between autism and death. As Turner notes, liminal subjects are often regarded as dangerous and polluted, perhaps because they are not easily classified or subject to the traditional power structures of the society. Liminal living is a form of ostracism or non-personhood that may feel like death, especially if you are in the company of a child who doesn't communicate.²⁹ Maurice's construction of the therapeutic journey as one of return to health and her narrative record of this journey can be read as her way of reincorporating herself and her children into mainstream society, returning her to her socially valued role of mother of children who will become independent adults. In fact, Maurice emphasises both her children's 'recovery' and the efficacy of behavioural therapy, providing detailed appendices with her children's diagnostic reports, instructional programs and evaluation data. She has subsequently written two other books about autism and takes an advocacy role in the field, suggesting the power of her reincorporation into mainstream society.

But Maurice's mode of reincorporation is not the only way parent-narrators use narrative to effect a change in their liminal status. The liminal has the power to change or reshape society. Because the 'basic building blocks of culture' are laid bare, the liminal can be transformational, and involve the 'reformulation of old elements in new patterns' (Turner, *The Forest* 110, 99). Forced to think about things that have previously been taken for granted, liminal subjects have the freedom to juggle with the factors of existence and create social and cultural change. As Turner says, 'Liminality, marginality, and structural inferiority are conditions in which are frequently generated myths, symbols, rituals, philosophical systems, and works of art' (*The Ritual* 128).

²⁸ Set against the invisible and ambiguous nature of the liminal, Whelan's ambiguous text and his desire for invisibility might make more sense.

²⁹ Antonetta points out Freud's reference to the figure of Death appearing as a mute character in German folklore.

While Maurice's act of aggregation relies on accepting a return to an unchanged mainstream society (albeit with new skills and knowledge), there are more progressive approaches that use the liminal's potential for change. The memoirs of both Paul Collins and Valerie Paradiz adopt this approach, resulting in counter-narratives that promote social change and can be read as examples of ethical cross-cultural interpretation.

Parents as Cross-cultural Translators

Many autistic people describe themselves as strangers or aliens on earth. Autistic writer and scientist Temple Grandin describes herself as 'an anthropologist on Mars' when she tries to understand the neurotypical world (Sacks, *An Anthropologist* 248). Other autistic people have used similar terminology (for example, Anna Hayward, Jasmine O'Neill, Jim Sinclair). The metaphor of the alien is interesting because it suggests that we recognise some fundamental difference between neurotypical and autistic people. It also suggests that this difference is unbridgeable, that both neurotypicals and autistics believe they are like two different species. As with all metaphors for the Other, this metaphor reflects a sense of quasi-oppositionality, of implicit inferiority and of unknowability. Aliens, by definition, are not human.

An alternative to this alien/human view is to view autism in the way we might view a different culture. Another culture might still be seen as unknown or foreign but is not necessarily viewed as inferior or non-human. This approach is grounded in the social-cultural paradigm of disability, where autism is viewed as one type of difference in a neurodiverse world. Savarese and Savarese provide a concise summary of the development of the neurodiversity movement, crediting autistic thinkers such as Kathleen Seidel, Jim Sinclair, Larry Arnold, Laura Tisoncik, Amanda Baggs and Donna Williams as the key group working online to cultivate autistic self-advocacy and the concept of neurodiversity. Websites such as *Neurodiversity.com*, and *Autistics.org* and the group Autism Network International have provided forums for the discussion and dissemination of these ideas.

Savarese and Savarese argue that:

A concept of neurodiversity can help us to remain attentive to a different sensibility – indeed a different way of being in, and perceiving, the world – while at the same time reminding us of the

need to construct the category of the human in the most capacious manner possible. (n.p.)

As some autistic people have noted, this ‘different way of being’ in the world can be viewed as a form of culture. Camille Clark suggests on her *Autism Diva* website that autistics are not claiming that autism *is* a culture but that when autistics meet (online or in person) they *share* a particular culture. In 2004, Amy Nelson posted a Declaration from the ‘autism community’, calling for autistics to be formally recognised as a minority group, autistic self-determination, and the removal of discrimination, including the effort to find a ‘cure’. This call for recognition as a minority group is based on the likely genetic origin of autism, the unique social networks created online by autistic people, and the existence of ‘cultural differences’ such as stimming (repetitive hand or body movements), differing perspectives on life and different language use.³⁰

The official United Nations description of culture says that ‘culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs’ (UNESCO). Autistic culture wouldn’t (yet) be categorised as a culture under this definition, however, nor would Deafness and there is a strongly held belief among the Deaf community (and many other disability activists) that deafness is part of a natural human variation, that Sign Languages are genuine languages and that Deaf Culture is a legitimate culture.

Autistic culture (or cultures) might be better described by taking a cultural studies definition, which views culture as a ‘collective subjectivity’ or ‘a way of life or outlook adopted by a community or social class’(Pertti 25). As more people on the autism spectrum are being diagnosed, including parents with their children, and as autistic-led groups become more influential, it seems possible that autistic differences may soon be considered characteristics of a minority culture. At the very least, autistics are likely to be seen as a minority group with some distinctive

³⁰ These views are by no means shared by all autistic people writing on the web or elsewhere. There are a wide range of positions held by autistic people on these matters; autistic activists are no more homogeneous in their views than any other type of activist. Similarly, autistic culture might really be autistic cultures, given the wide range of individuals who receive an autism spectrum disorder diagnosis or have self-diagnosed as autistic.

linguistic and cultural features. This is not just a matter of description. As Carol Padden says about Deaf culture, ‘To use a cultural definition is not only to assert a new frame of reference, but to consciously reject an older one’ (85) – in this case the older but still predominant medical model of autism as deficit. Like the Deaf community, gay community and some Indigenous communities in western countries, the autistic community is not bounded and separate from other communities, but living amongst and within mainstream culture, with the internet providing the key meeting point.³¹

Considering autism in this light, neurotypical parents of autistic children may well find that Grandin’s trope of being an anthropologist is reversed.³² The parent can feel like the anthropologist, or ethnographer, in the foreign world of autism. And just as ethnography has been described as the ‘translation’ of another culture into a form comprehensible to the west (Dingwaney 4), so might a parent feel she is translating the world of her child to others. As in translation and ethnography, there is a power imbalance, with the ethnographer/parent being the one who comes from the dominant culture and is the agent of translation.³³ Parents writing memoirs about their autistic children may be compared with ethnographers in the sense that they are attempting to interpret, perhaps even recuperate, aspects of their child’s existence, in particular those aspects which are viewed as alien. The result of this process of translation will be the life writing text, the parent completing translation as both process and product.

Based on Scott-Hoy’s definition of auto-ethnography as ‘a blend of ethnography and autobiographical writing that incorporates elements of one’s own life experience when writing about others’ (276), a neurotypical person writing about autistic people may be considered to be writing auto-ethnographically. In the case of parents of autistic children, however, the majority write a memoir about their own child (rather than a group of children or autistic culture) and the majority are laypeople rather than

³¹ And more local or national events specifically for autistic people, such as Autreat in the US.

³² There are, of course, autistic parents of autistic children, but the majority of memoirs about autistic children are written by parents who are either neurotypical or who were not aware of being autistic when they became parents (as in the case of Valerie Paradiž). My particular interest here is the way neurotypical parents, like me, write about their autistic children.

³³ The parent, of course, has an additional source of power by virtue of his or her role as parent and care-giver.

trained anthropologists or ethnographers.³⁴ These memoirs, then, are not generally read as auto-ethnography. In my own case, I was very resistant to viewing my work as auto-ethnographic because I interpreted this to mean situating my son as representative of a group of colonised subjects. I wanted to write about my son as an individual whilst also acknowledging the impact of cultural mores upon him and I believed that the focus of my work was around my relationship with him. I felt uncomfortable about the anthropological aspect of the ethnographic enterprise as I then understood it.³⁵ However, it was very clear to me that a key part of my role as parent, as well as memoirist, was interpreting my child and the world to each other.

All parents interpret the world for their babies and teach their children the symbolic use of language. However, parents of children with communication or cognitive disabilities find themselves interpreting their child to the world and the world to their child to a greater extent and for longer than other parents. Even as the child becomes an adult, this role as mediator may continue. The nature of the interpretation is different, too, for the parent of an autistic child. Even though my son uses language well and understands a lot of what other people say, I still interpret or translate some of the gestural, social and emotional meanings, idioms and other aspects of communication for him. In my memoir, I am performing a further act of interpretation, because, as a neurotypical parent, I am turning my son's life into a text for neurotypical readers. In spite of my resistance to the idea of being an ethnographer, I can now see that these interpretative acts are similar to those interpretative acts of ethnography.

I suggest, then, that a parent writing about an autistic child is writing a form of cross-cultural memoir, and that the act of interpretation is similar to the act of cross-cultural translation. This being the case, the literature on cross-cultural translation is relevant in reading parental autism memoirs. In particular, the literature on ethical translation is relevant, in that it addresses the act of translation or interpretation as a politically charged act that can work to erase difference, to exaggerate difference

³⁴ One exception would be anthropologist Roy Richard Grinker, author of *Unstrange Minds*.

³⁵ My views changed partly through my attendance at the 2008 IABA Conference, where I first presented a conference paper on the issue of parental memoirs and translation (Robertson, *Cross-cultural*).

through ‘othering’, or to record difference in a way that allows it expression and value but not freak status.

Anuradha Dingwaney suggests that contemporary translation theory calls for self-consciousness or self-reflexiveness and making translation visible in the work. She argues that the process of translation always entails violence, most especially when there is a power asymmetry involved (for example when westerners translate material from developing countries). This violence can involve cultural differences being assimilated and familiarised, erasing their difference through the desire to render them accessible. Dingwaney calls for translators to allow difference to be ‘mediated and recorded, not sacrificed or appropriated’ (10). Lawrence Venuti, arguing that translation is always interpretation, suggests that an ethical translation avoids forcibly assimilating the foreign to dominant values and thus erasing all sense of foreignness. He notes the west’s preference for ‘fluency’ and suggests the need for ‘resistant strategies’ to allow the translation to function as a ‘locus of difference’ (quoted in Maier 24-5). The notion that cultural differences risk being erased by the dominant culture is highly relevant to neurotypical writings about autism, as I discuss below. In fact, it mirrors (neurotypical) therapeutic interventions with autistic people, as therapists and parents aim to prevent their children from ‘stimming’, demonstrating other ‘inappropriate’ body manoeuvres and from speaking in scripts or quotes (echolalia).

Carol Maier argues that there is a space between languages, where language breaks down under the pressure to transmit the unknown, and that translators may try to avoid this space because of their discomfort with it. She says,

Hence, there is an almost resolute avoidance of the ‘between’ in which that breakdown occurs and a failure to acknowledge the potential for human interaction that occurs when one language proves inadequate in the presence of another. (22)

While Maier is speaking about different languages here, again, there is a similarity between this and the unknown ‘between’ space that neurotypicals may experience when faced with autistic communication (which may be read as non-communication).

Venuti argues that translation ‘wields enormous power in constructing representations of foreign cultures’ (67) and calls for ethical translations to decentre

ethnocentric views and create texts that are potential sources of cultural change. Maier, however, warns that a focus on difference can act to blur the existence of inequality between translator and translated. Her focus on untranslatability or withholding translation acknowledges the ‘between’ place of breakdown and leads to a focus on the process of translation, rather than just the product. She argues that translators need to become intimate readers through close association with the translated. She suggests that once discussion about translation ceases to focus on terms of equivalence and the finished product, it can be considered instead as ‘a practice in which it is possible to approach both difference and inequality interrogatively’ (29). The translator can then seek new conceptual frames that will present one culture to another. She argues that if translation is a practice not a product, then its end is ‘the prompting of rather than the resolution of an inquiry’ (31). As with Dingwaney’s call for self-reflexivity, Maier recommends foregrounding the process of translation by acknowledging the complexities of the task and choices made.

Just as the western translator comes from the dominant culture, so does the parent translator, making power inequalities relevant to parent memoirs. Using cross-cultural translation as a frame, I examine whether the practice of writing about an autistic child may allow the parent to address difference and inequality in self-reflexive ways that give space to both the ‘foreignness of autism’ and the breakdowns in translation. If, as I suggest earlier, the parent is writing to create narrativity and therefore value for the child, then does this pressure towards fluency and the domestication of difference compromise cross-cultural translation? Does the parent’s desire to rescue both child and self from liminality mean that the act of translation results in assimilation of the child into the dominant world of the neurotypical? I explore these questions in relation to two memoirs in Chapter 4.

Chapter Four: Border Crossing

‘Permanent outsiders’

[I]t was only with the belated translation of Asperger that many English speakers began to understand that autism included a whole spectrum of permanent outsiders, some so well adapted that they scarcely realised they had been autistic all along. Rather than helpless primal casualties, Asperger insisted, autists were talented eccentrics living among us, albeit in a sphere of their own. (Collins 87-8)

Tracing the ‘cognitive underground’ of people with autism is a key feature of *Not Even Wrong: A Father’s Journey into the Lost History of Autism* published by US historian and editor Paul Collins in 2004. The book is a collection of vignettes of the author’s family life as he and his wife discover their son is autistic, and a series of stories about current and historical figures who might have been autistic or who study autism. Collins writes about Peter the Wild Boy, mathematician Alan Turing, Bill Gates, Septimus Piesse (inventor of the odophone), James Pullen (autistic wood carver and sculptor), the artist Joseph Cornell and Henry Darger, author of the world’s longest work of fiction and a ten year weather diary. He meets Simon Baron-Cohen, a world renowned autism researcher, goes to Vienna to see where Hans Asperger once worked and visits the Sanger Correctional Facility to watch prisoners train service dogs for use by autistics.

Morgan, Collins’ son, is between two and four years old in this book. As the book progresses, Morgan goes from diagnosis to early intervention and he starts using language to make requests. His parents don’t know whether he’ll attend a mainstream school, how much language he’ll learn, how well he will be able to function in daily life or social situations. They aren’t sure if they should or will have another child or not (though they decide they want to). The life of their son has suddenly gone from the normal, predictable developmental path to something completely unknown to them: ‘How can it be that we left our house an hour ago with a healthy toddler, and returned with a disabled one?’ (8). As the unknown strikes, Collins starts narrating his son’s life for a book. For a parent, with the shock of a

diagnosis like autism, comes the loss of both past and future. The past is lost because it is changed: instead of ‘healthy toddler’, Collins now has a disabled son. The future is lost because the parents’ projected (though often unarticulated) sense of their child’s future is no longer possible as a destination. The parents’ beliefs and expectations are interrupted and the future of the past is lost, together with any clear sense of the future of the current moment. As David Carr says, ‘The present is only possible for us if it is framed and set off against a retained past and a potentially envisaged future’ (60). These losses and the sense that the child has changed, contribute to the parent’s desire to create a new identity narrative for the child. It’s not surprising then, that Collins also writes about other autistic people, past and present. He is linking Peter the Wild Boy and Bill Gates to his own son, mapping a generational narrative about autism which gives his son past and future, a sense of continuity through time, essential for narrative identity. Where Morgan’s own past and future are disrupted and unknown, Collins can substitute a set of ancestors and peers, each with their own story, to fill the gap. He addresses the challenge of creating narrativity for his son through the use of other people’s narratives.

The subtitle of the book makes it clear that Collins’ quest is to establish a web of connections between different people who may have been autistic. For the most part, the people he writes about weren’t actually ‘lost’ to history, but they were marginal. Collins is trying to recuperate them, not just in terms of getting the historical information clear, but also in terms of their value. He is doing Frank’s work of moral non-fiction by finding grounds for asserting the value of his child and his child’s larger autistic family. He approaches this overtly when he notes that some significant discoveries of science and art have been made by people who were possibly autistic, as a result of their extraordinary concentration skills and lateral thinking. Collins suggests that, if we need the Isaac Newtons, Bill Gates, and Glenn Goulds of this world (whom he suggests were or are autistic), then we must also have the more severely disabled autistic people who aren’t scientists, inventors or artists, but still dedicate the same amount of effort to their own obsessions.

Collins is advancing a utilitarian view of value here – if we want talent we must also have and value severe disability. At other times in the book, however, he approaches the question of value differently. His biggest question is: ‘What does it mean to be *a person*? To be human?’ (34; emphasis in original) Collins asks this

question in the context of Peter the Wild Boy, but really he is asking about his own son. He answers this question later in the book.

Autists are described by others – and by themselves – as aliens among humans. But there’s an irony to this, for precisely the opposite is true. They are us, and to understand them is to begin to understand what it means to be human. Think of it: a disability is usually defined in terms of what is missing...But autism is *an ability and a disability*: it is as much about what is abundant as what is missing, an overexpression of the very traits that make our species unique. Other animals are social, but only humans are capable of abstract logic. The autistic outhuman the humans, and we can scarcely recognise the result. (161; emphasis in original)

Collins’ argument here is that autism is an over-expression of certain attributes that are, if expressed normally, fundamental to our understanding of being human. This excess of human-ness (an excess of abstract logic) must be valued because it is what divides humans from other species. This approach might be interpreted as a variant on one often cited: that autism is important because it shows us – through lack – what it is we value about being human. But the argument that Morgan and other autistics have value because they have a higher capacity to use abstract logic is more appealing than convincing. Firstly, not all autistic people demonstrate a capacity for abstract logic, let alone an over-expression of it. Secondly, it’s not clear just how exhibiting an over abundance of something that separates humans from other animals creates value.

Collins’ goal of convincing a reader to care about and value Morgan is achieved, I suggest, not through his philosophical arguments, nor through his stories of other autistics, but through his representation of his son, in particular in the respectful way he mediates between Morgan and the reader. We first see Morgan looking closely at a steamer basket and saying ‘Da-ya dicky-doe’, making his father realise that having a child ‘forces you to retrace the steps of things you’ve forgotten you ever learned, like...how to stare so intently at a kitchen implement that it becomes a completely abstract object’ (3). Morgan runs into the bedroom and turns the pages of *Merck Manual*, a medical text. His father tickles him and Morgan ‘collapses against me in hysterical giggling’ (5). In this way, Collins presents Morgan as a happy, alert

toddler with a strong relationship to his parents. But he also shows that Morgan's speech and interests are unusual for a two year old. He pre-emptively the way Morgan is going to force his father to retrace his steps and take a new view of the world.

There are many scenes of Morgan being himself in this book. Here is Morgan when a new piano is delivered:

Plink plink bruum: his hands dash madly up and down the keyboard, he stretches his arms out at full length to span three octaves and batters his hands against the white keys until a C-major roar fills the room.

He stops to leap up and down. 'Yay! Yayy! Yyyyyyy!!'

Then he pumps in a bunch of breath, hyperventilating, rattles his head, and batters away at the keyboard for another five minutes solid while Jennifer writes a check to the moving guy, who is watching in unabashed fascination at the performance.

'*Yes no ABCDEFG Twinkle Twinkle!*' Morgan hollers as his fists pound out time on the keys. (14; emphasis in original)

Not long after this, Collins takes Morgan for an evaluation with child development experts. While the adults try to get Morgan to respond to them and do certain activities, Morgan tries to play with the camera videoing the session. Similarly, Collins describes Morgan at home watching a video:

Morgan trampolines back and forth between the two mattresses in our bedroom – his little bed and our big bed – breathlessly singing along with the video. He knows every word of the tape. He can bounce like this for hours, and does; the entire house should be covered in bounceable elastic, as far as he's concerned.

And then a song comes on. He pauses, alarmed.

'Piano!' he yells.

Morgan grabs Big Bird and leaps off the bed, sprints into the living room, and throws the doll onto the piano bench. Then he scrambles onto the bench next to Big Bird.

'*Whoo!*' He pounds the piano keys. (143; emphasis in original)

In this and many other descriptions of Morgan, even those where he is unhappy or doing things his parents don't want him to do, there is energy and intent. Most of these descriptions are value-free; Collins tries not to judge his son's actions or words.

He doesn't try to make Morgan look or sound like a typical toddler. He is clear that Morgan's actions and speech are odd and often puzzling and he allows the unknowability into his text. He is not assimilating or erasing Morgan's differences but rather mediating and recording them, meeting Dingwaney's criterion for good translation.

We see Morgan moving wood chips from one area to another in the park, eating icecream without smiling, collecting 'broken bits of language like a magpie' (81), singing the alphabet, demanding popcorn and plucking the wires inside a piano at the local store. We are also shown that he sometimes bites people when he's upset, that he will refuse to do certain things and throw a tantrum in the supermarket. By the end of the book, the reader has come to know Morgan and his family. Although Morgan can't narrate his own life (yet), we see his actions as purposeful, we see his parents responding to him, we see him both resisting and cooperating with his parents, and we see in this interaction the co-construction of Morgan's sense of self. Collins is able to represent Morgan and his difference without either minimising this difference or turning him into a freak. He is able to 'send the reader abroad' (Venuti) rather than domesticate autism by erasing its strangeness for the non-autistic reader.

By recording Morgan's behaviour in language that is free from overt judgement, Collins presents it (and by implication the behaviour of other autistic people) on its own terms. That is, he avoids using medical terms to describe his son, unless he is reporting the dialogue of medical professionals. We can compare this approach to Maurice's, who adopts medical language such as 'stereotypical' and 'self-stimulatory' to describe her children's behaviour. We might read this as the foreign being forcibly assimilated into dominant values – in this case, medical discourse and taxonomy. Collins shows the reader the behaviour rather than choosing to describe it using a medical frame. Similarly, Maurice's text only allows her children to be characterised when they are 'normal' and their foreignness is erased. Morgan's character is clear to us from the beginning of Collins' memoir, even though we may not understand his speech or why he is doing what he does.

Collins does not avoid what Maier describes as the space where language breaks down and the unknown lies. In fact, he dramatises this space in his story about Morgan suddenly saying, 'I feel all alone' (170). Collins is terribly upset to hear his son say this and keeps telling Morgan that he's not alone. Morgan continues to say,

‘I feel all alone’, and Collins gets distraught trying to comfort him and trying not to dwell on his own fears for Morgan’s future. Eventually, Collins realises that Morgan is actually singing along with a tape and that the words he is singing are ‘Pastry all day long!’ (175). The purpose of this anecdote, I think, is not about Morgan’s articulation but rather about the large gulf that Collins recognises lies between him and his much-loved son. He desperately tries to understand, help, protect and teach Morgan, but his research on autism and on autistic individuals has shown him that Morgan’s future is already likely to be more challenging than are the futures of his neurotypical peers. The space between him and his son is simply a domestic version of the space between mainstream and autistic culture.

When Morgan is three and a half, he is enrolled into a specialist autism class. As soon as the family arrives on the first day, Morgan joins in, playing alongside other autistic children, and his parents feel as though they are watching ‘a family reunion’ (223). Looking at the room full of autistic children, Collins says,

There is no awkwardness among them: they are equals. It is as if we have brought a seal to the ocean and watched him shuffle awkwardly off the land to glide effortlessly through the waves, finally within the world he was made for all along. (224)

The metaphor of the seal is telling: not only does it link to dilemmas about mainstream education and life (as opposed to life in a tributary), it also avoids the common stock of autism metaphors (puzzles, battles, aliens and so on). While it is an animal metaphor, it involves a reversal, whereby neurotypical culture (the land) is challenging and autistic culture (the sea) is represented as natural, welcoming and egalitarian.

It is clear from the title of this book that it was written as a form of counter-narrative. The phrase ‘not even wrong’ is taken by Collins from physicist Wolfgang Pauli who used it to deride colleagues who disagreed with him, suggesting that their comments and questions were so off-base that they were irrelevant. Collins applies it to autism by claiming that autistics are working from such a different set of parameters in the world that they are not even wrong, just different. This is a way of questioning the polarities that underlie the traditional conception of disability as a medical category rather than a social, cultural and political one.

But the suggestion that autistics are ‘not even wrong’ might also be read as an attempt by Collins to seek (in Maier’s words) a new conceptual frame to present one culture to another. Collins doesn’t talk overtly about autistic culture as such – his focus is on autistic individuals – but the idea is implied nonetheless. By researching and writing about several generations of autistics, Collins has given himself a familiarity with autistic culture, the sort of intimacy that Maier argues self-reflexive translation requires. Visiting a special school for autistics, Collins recognises both that their behaviour would be unacceptable in a mainstream school and that this behaviour seems appropriate for autistics, including his own son. Even as he sees the potential benefits of integrating Morgan into mainstream society, Collins questions the values inherent in these benefits.

Autists are the ultimate square pegs, and the problem with pounding a square peg into a round hole is not that the hammering is hard work. It’s that you are destroying the peg. What if normal school makes you abnormally miserable? And what if growing up into normal society makes you a miserable adult? Is that success? Is *that* normal? Do you want to be in the mainstream if it’s going to drown you? (225; emphasis in original)

As both parent and ethnographer, Collins raises questions here rather than providing answers. This gives the book a kind of openness that allows readers to make different interpretations and to interpret the ‘lost history of autism’ in their own ways.

To compare Collins’ book with Maurice’s once again, whereas *Not Even Wrong* asks questions, *Let Me Hear Your Voice* provides answers. Maurice has written a very moving book, but her narrative is not self-reflexive or open to different moral orientations. If she were an ethnographer, she would be one who never dared visit the other culture. In fact, for a neurotypical parent to enter the space of autism – in life or in narrative – is very challenging, as Collins’ book demonstrates through the continued displacement of his son’s story with stories about autism researchers and historical figures with autism. The pain of writing about his son is continually interrupted by a story about an historical figure or a new research facility to visit. Although he rarely expresses it, Collins is aware of the liminal status of the disabled and their families and he avoids the discomfort of this loneliness with his excursions

into history. Maurice, Whelan and LaSalle all use their memoirs as a kind of act of reintegration from the liminal to the mainstream. For Collins, the recuperation of an alternative history of autism, a kind of genealogy into which his son may be fitted, appears to achieve the reincorporation process. His transition is not so much back into mainstream society as it is into a moral arena: his book stakes a claim for the value of his son by virtue of his humanity. For Collins, liminality may have fulfilled the role of a place of potential transformation, where alternative social arrangements can be dreamt.

With his focus on autistic history, Collins has decentred dominant cultural mores in his narrative and interrogated both difference and inequality. In his act of cross-cultural translation, Collins uses his privileged role as a member of a dominant culture to present and begin to validate a peripheral culture. His memoir provides an example of how a parent can mediate between two cultures and create a text which allows for the possibility of cultural change. This cultural change is not enacted in the book, leaving Collins' project of validating autistic culture unfinished. Morgan is still very young at the end of the book and most of the complex dilemmas of life as an autistic person in a neurotypical world, and narrating that life, are left unexplored. As Osteen points out, 'Collins lacks the experience that would lend authority to his conclusions; it's hard not to feel that he has written the book too soon' (20). In contrast, *Elijah's Cup* explores these issues and takes Collins' project one step further.

'Cracking code'

Each of Elijah's actions became well-rehearsed events. Each word spoken was echolalic. The long days trapped inside the house and inside the repetitions forced themselves deep into my psyche. I began having dreams at night that I can describe only as dreams of autistic structures of the mind. I woke up in sweats, having just executed long calculations. They were extended logic problems, replete with scientific symbols that I freely understood and manipulated with ease, translations of a kind, from neurotypical to autistic thinking. When I awakened from these philosophical excursions, I felt deep physical relief. It was as if I had cracked a code, as if I'd been returned to a

former way of life that I had once belonged to but had long forgotten.

(Paradiž, *Elijah's Cup* 91-2)

In *Elijah's Cup: A Family's Journey into the Community and Culture of High-Functioning Autism and Asperger's Syndrome*, published in 2002, Valerie Paradiž describes the seizures her son Elijah experienced, his diagnosis with autism and their joint exploration of autistic culture. Unlike all the other memoirs discussed, Paradiž clearly identifies autistic culture and says in her preface that she is publishing her book in the hope that readers will learn, as she has, 'to think of autism not as a *mental illness* that absolutely needs a cure, but rather as a *way of life* that possesses a deep history and a rich culture' (xi; emphasis in original). In a sense her book picks up where Collins' leaves off, taking his social history of autism a step further and embracing the notion of a distinctive and valuable autistic culture and community.

Paradiž early on identifies herself as someone who likes 'crossing cultural boundaries' (xi) and, interestingly, she works as a German-English translator. She also notes (for example, in the quote above) that she has a deep familiarity with aspects of autism. In retrospect, she sees that her father, paternal grandmother and she herself seem to possess 'autistic shadow' traits or manifest a 'broader autism phenotype' (87). In her case, this appears as the desire for sameness, preference for solitary activities, social anxiety and periods of preoccupation with tornadoes. Some years later and not included in this memoir, Paradiž is actually diagnosed with Asperger's Syndrome (Paradiž, *Leaving the Ivory Tower*). When writing *Elijah's Cup*, however, she considers herself neurotypical but with some shadow autistic traits. When Elijah is diagnosed, she knows very little about autism, but she is not afraid of it.

It is not difficult, then, for Paradiž to spend time with autistic people. She may find Elijah's behaviour challenging, but she doesn't seem to find the diagnosis of autism challenging. Early in the book, Paradiž reports a conversation with a babysitter where Paradiž is concerned about Elijah's health. The babysitter, Sharron, says, "Oh, you don't need to worry. He's just autistic. I've had autistic friends before." (40). In this way, the idea of autism is normalised and linked with friendship. When a neurologist first asks Paradiž if she has considered Elijah might be autistic, she acknowledges that she has:

I answer without a second thought, though why I say it is beyond my comprehension. I know nothing about autism, and yet her words are neither startling nor upsetting. In some inexplicable fashion, it has taken up a presence in my mind. Perhaps it came from Sharron. The mist is rising. Autism. It's familiar. Even kindred. (41)

Paradiž, then, has one foot in autistic culture and one foot in neurotypical culture. She does her parental translation partly from within the foreign culture. This doesn't make it easy. Paradiž describes how she must learn how to 'wear Elijah's' autism and to adapt to her new role: 'I have become a single mother of a disabled child' (74). She follows the suggested therapeutic interventions but she struggles with the pressure she feels she is placing on Elijah to be 'normal'. She wonders if echolalia is just the pointless repetition of words or a 'particular expression of consciousness' (104). She finds the medical language around autism to be demeaning and yearns to hear Elijah's own 'voice of experience', unencumbered by expert observers or even her own voice (71). In the end, she agrees with the specialists that it is right to teach Elijah to speak, self-care and make friends. But she doesn't want to adopt the cultural attitudes that frame autism within the health system. She will use therapeutic interventions without adopting the medical paradigm of disability. She continues to want her son to be able to express himself, in all his foreignness: 'I want to cross borders with Elijah and help him find the authentic expression for his experience' (72).

In the final scene of the book, Elijah is ten and has just learned about similes from his reading tutor, describing his mother's nose as 'silver like Russian coins!' (218). He then talks obsessively about Gameboy, his current interest. His mother pretends to be interested 'for the umpteenth time' (218). Then Elijah switches to telling Paradiž about a dream he had where he was a detective saving his friends in the playground. He ends the story by telling his mother that she was 'cracking code' in the dream, suggesting that he, too, recognises her role as a mediator between him and the neurotypical world.

In spite of her success in decoding autistic culture, Paradiž clearly recognises the 'space between' that Maier speaks of and expresses this through her use of glass/mirror imagery. Describing the two year old Elijah looking through a window but not looking at what she is pointing towards, she says, 'The glass had something

to do with it. Glass has inscrutable importance. It's one of the places where we stray from one another. One of the places where communication fails us' (3). She links the notion of glass and borders with repetition: 'the repetition is compelling, a mirror of internal drama and development. It is a place of border crossings, a place under glass, suspended somewhere between subject and object' (159). Referring to the autobiographical writings of Temple Grandin, Donna Williams and Wendy Lawson, Paradiž says, 'Glass is the symbolic medium of division between autistic and nonautistic life...[Autistic vision is] another order of vision that in spite of a translucent medium causes profound separations' (169). Glass is an interesting image for the divide between autistic and neurotypical life because it is invisible, as autism often is, and yet is about vision. Glass appears neutral, but we each see something different through it. It provides a clear border between inside and outside or one room and another room and yet glass windows and doors can be opened (or shattered). It acts as a subtle but effective representation of the 'pressure to transmit the unknown' and the breakdown that happens when 'one language [or culture] proves inadequate in the presence of another' (Maier 22).

Elijah's Cup is an artfully written book but one which never succumbs to mere fluency or polish. There is always narrative resistance. Elijah's seizures are described using images of flowers and blossoming, creating dissonance for the reader to convey the dissonance and loss of seizure. After twenty-five pages describing the seizures and medical treatments, we are suddenly confronted with a passage from Kafka's *The Castle*, which Paradiž is translating for a client. When Paradiž is trying to think about Elijah's diagnosis, she reads Nietzsche (as part of her PhD examination preparation). These leaps within the text work to defamiliarise. We are made to question the language and efficacy of medicine by Paradiž's quotes from Nietzsche's *The Gay Science*. The transitions, which include repetitive phrases and questions, also convey a life of both interruption and repetition. Paradiž shows Elijah's repetitive behaviour but also replicates it in the structure of the book. In this way, she presents the difference of autism, both in her scenes with Elijah and in the larger pattern of her memoir. The disruptions are particularly noticeable leading up to a scene where Paradiž experiences a breakdown from too much work, worry and pressure. Unlike *Not Even Wrong*, there is no sense here that Paradiž's excursions

into research are an avoidance of pain, because her narrative very clearly articulates and stays with many moments of grief and loss.

Soon after her breakdown, Paradiž describes going with Elijah to buy and then release a helium filled balloon, this being his fixation of the moment.

There are moments such as these when life with Elijah becomes so narrow, so rigidly charted and overdetermined in every action and word, that I could burst out in fits of anger and resentment. But – I don't know what comes over me – I suddenly see the poignant humour of it all, and I laugh out loud at this crazy, lonely comedy routine we've put together, the one I have no chance of escaping. (116)

From this moment, the text seems less dislocated, as if Paradiž had now accepted that her life would be full of disruption and repetition. She starts to wonder about the social history of autism, doing research on Einstein, Andy Warhol, Wittgenstein and comedian Andy Kaufman. She and Elijah (now six) go on their first Autreat (a retreat for autistic people organised by the Autism Network International) and meet Jim Sinclair, one of the founders of Autreat. The second half of *Elijah's Cup* is more expository and less lyrical than the first half. The focus is on autistic culture and the text is written perhaps as much to educate the reader as to tell the personal story of Paradiž and her son. Elijah continues to develop and change, deciding that he wants to be a comedian for example. But he also continues to demonstrate autistic preferences – repetition, concrete language, stimming – and his mother doesn't try to stop him.

Near the end of the book, Paradiž writes, 'Elijah's cup is full. He has his special interests. He has his comedy and his ups and downs. He has his autistic mentors and his friends' (199), thus completing the sense that Elijah, as well as his mother, has come to terms with being autistic. This is a long way from the first mention of Elijah's cup, when Paradiž tries to work out what it means to do an MRI on her son. She wonders if it is like putting a saucer over a cup, or locking the door at Passover and trying to hold in the promise of Elijah – the promise that the Messiah will come one day. The medicines she gives Elijah are described as a 'cup of violence' and poison (13). By the end of the book, Elijah's cup is full and once again the door is open with promise.

Paradiž achieves her narrative structure partly through the passing of time, as her book covers around ten years, and partly through the use of metaphors such as Elijah's cup and glass. But, like Collins, she also creates narrative through her excursions into European literature and the lives and work of autistic artists and thinkers. The social history of autism once again works alongside the individual story to create an identity narrative.

Like the other memoirs discussed, one of the aims of Paradiž's work appears to be to stake a claim for the value of her son. In this case, she is also attempting to argue for the value of other people with autism and autistic culture. She rejects both the symbolic and medical paradigms of disability and embraces the social-cultural paradigm and the disability rights movement. Unlike Collins, Paradiž clearly identifies the borderland between neurotypical culture and autistic culture and suggests that she is happy to cross over that border and traverse between two cultures. Like Collins, she comes primarily from the dominant culture but presents and validates the peripheral culture. Where Collins suggests possible change in the future, Paradiž's work enacts this change through her embrace of autistic culture. As an ethnographer and translator, she fully immerses herself in the other culture and argues for social and political change. Where Collins decentres dominant cultural mores, Paradiž goes further to put autistic cultural mores centre-stage. *Elijah's Cup* doesn't act to reincorporate Paradiž and her son into mainstream society. Rather, they are incorporated into the alternative culture of autism, shifting the liminality of disability into a vision of centrality.

This vision of autistic culture as centre is most effective in the scenes of Paradiž and Elijah at Autreat or when they are socialising with friends. However much a parent may surround her child with autistic mentors and support autistic culture, the reality for most autistic children is that they will not go to a school designed around their own needs (though there are now some specialist schools that attempt this) and they will find it difficult to thrive in a majority neurotypical culture once they leave school. The difficulty of life as an autistic person is not resolved by a narrative that places autistic values at the centre, but it is part of the impetus behind the memoirs of Collins and Paradiž. In reality, both parents know their child will be an outsider, but they hope to make this less difficult through their ability to convey to others the value of autistic people.

Collins ends his book with a scene of Morgan having a tantrum in the supermarket. People are staring at him but he doesn't care. He writes, 'it's not what they think. It's not a tragedy, it's not a sad story, it's not the movie of the week. It's my family' (229). He is trying to make the point that his family is both different from, but also the same as, other families. Like Paradiž, he rejects nostalgia for his pre-disabled child (or imagined child) and prior identity as parent. Like Paradiž, he refuses to look for religious or moral compensations in this new parenting role. He notes his son's developments (the tantrum in the supermarket being a sign of emotional development in that it arose out of Morgan missing his father's company) and is proud of these without having recourse to the rhetoric of triumph. The attempt to make his family both ordinary and autistic is limited by Morgan's youth (and Collins' limited contact with autism) and the fact that Collins avoids addressing the depth of his feelings around his son's present and future.

Elijah's Cup ends more effectively because Paradiž appears to have resolved her own feelings about her son, his disability and her own role as mother. She describes her own social and intellectual experiences in the book, demonstrating that she is not just a mother but has other interests, roles and activities in her life. At the end of her book, Elijah (now ten) tells his mum that he can predict the future.

'In two years...'

'Yeah?'

'I'll be twelve years old.' (219)

This ending not only allows Elijah the last (and accurate) word. It also enables Paradiž to acknowledge the uncertainty of the future for Elijah (they can only be sure of his chronological age) while also suggesting that this uncertainty is no different from that experienced by other children. If the stasis of disability results in an unpredictable story 'inassimilable within the usual narrative formulas' (Couser, *Vulnerable* 150), then perhaps Paradiž is suggesting here that all of us have unpredictable life stories but that only those of us living with disability are aware of this. The ordinary and different are held, not in opposition but in conjunction with one another.

This conjunction is reminiscent of Frank's quest story and what he calls the communicative body, where contingency is accepted and the result of the quest journey is offered as a gift to others. Whilst all the memoirs discussed were written

partly to help other parents of autistic children, I believe that *Elijah's Cup* has the most to offer a parent who wishes to understand and embrace their child's experiences. Maurice takes the role of saviour as well as parent-narrator in her book. LaSalle takes the role of explorer, attempting to understand through her memoir, while Whelan is both explorer and, as if in spite of himself, saviour. Both Collins and Paradiž are translators and mediators, crossing the borders between autistic and neurotypical cultures, but only Paradiž manages to allow autism its full difference and its ordinariness. It is a counter-narrative that represents Elijah and his disability in an ethical and progressive way and allows us to re-vision the future for children like Elijah.

Conclusion

In this exegesis, I have analysed the different ways five published parental memoirs about autistic children address the challenge of ethical representation, and the extent to which the narratives can be read as counter-narratives to the dominant popular and medical views about autism. Starting with a discussion of *Let Me Hear Your Voice*, which I consider to be the least progressive of these memoirs, I then discussed *The Other Country* and *Finding Ben*, arguing that both texts can be read as counter-narratives that are also, to some extent, complicit with certain pervasive master narratives around autism and disability. The ambivalence and contradictions within these two texts allow a range of readings and reflect the complex experience of parenting a child with a disability. In my discussion of *Not Even Wrong* and *Elijah's Cup*, I demonstrated that they are more effective as counter-narratives, reflecting the social-cultural paradigm of disability and allowing autistic people autonomy and agency. Both authors take a role as cross-cultural translator (rather than parent-saviour or explorer), interrogating neurotypical values and embracing alternative, autistic values. I also argued that the work of these parental memoirs is not only to counter public understandings of autism but also to reclaim the value of the autistic child and to reintegrate both parent and child into either mainstream or autistic culture.

While *Elijah's Cup* is the most progressive text discussed, it raises some dilemmas as a model for other parent memoirists, especially those, like me, who identify as neurotypical. Parents may not wish to make the shift into autistic culture; we may wish to be free to traverse the borders, encouraging and supporting the autistic child to do the same. We may want to interrogate and decentre the cultural mores of neurotypical life without making autistic culture a new centre. Our vision of cultural and political change may involve a more complex mediation and translation act that allows for ambivalence and contradiction around our own role as parents and writers.

While none of these memoirs presented me with a direct model, my exploration has strengthened my own creative work and influenced the way it developed. My

research has meant that my own thinking has shifted so that I now view disability as a socio-cultural construction and attempt to parent my son from a neurodiversity perspective. In many ways, my creative work charts this shift rather than results from it. It is a record of my own development as a parent and a writer over a period of five years and if I wrote it from the beginning now, I would write something quite different. While I was always aware of trying to write a counter-narrative, the nature of the task and the way that the memoir form acts to facilitate complicity rather than challenge, was something I had to discover from my research and from my own creative practice. Like Michael Whelan, I knew I didn't want to write a heroic recovery story but found myself slipping into writing scenes that demonstrated my son's development. I wanted to show my son's individuality but also make a link with other autistic people, to represent his actions and words accurately but not present him as a stereotype. I wanted to allow his differences but also reflect his similarities and ordinariness. Like Barbara LaSalle, I wanted to demonstrate aspects of my own 'ableism' and how my views changed, though without divorcing myself and my son from broader cultural influences. I wanted to interrogate society's values and assumptions and allow for the possibility of change.

In attempting to achieve these goals, a key aspect for me was the form of my work. I decided to avoid telling a chronological story about my son and to write instead a series of themed autobiographical essays. I chose the personal essay because it is an ideal form for exploring uncertainties, such as parenting. The essay's etymology of attempting, testing or trying out something fits very clearly with my approach both to parenting and to writing about that parenting. The 'irregular undigested piece' of writing that Samuel Johnson (Oxford University Press) refers to is, I think, a good description of my own creative work.³⁶

I believe that the essay form also lends itself to counter-narratives, including disability counter-narratives. Rosemarie Garland-Thomson, building on Caroline Bynum's discussion about metamorphosis stories, suggests that the notion that 'shape structures story' could be 'the informing principle of disability identity'

³⁶ There is a significant body of literature on the essay form, some of which addresses the way essays are used by those who are marginalised or were previously silenced. While this literature was useful to me, I do not have space to explore it in this exegesis and instead provide a summary of some of the key factors leading to my choice of the essay form.

(*Shape Structures Story* 114). She notes that one of the most enduring cultural fantasies of contemporary life is a belief in bodily stability, or more precisely a belief that bodily transformation (ageing) is predictable and tractable. Garland-Thomson argues that ‘we use the cultural story that we call normalcy to structure our shapes’ (114). That is, we use an abstract ideal of normal human development – a story of predictable life passage – to understand our bodily selves. Disability, in contrast, insists that shape structures story, that our bodies structure the narrative.

As I discussed earlier, a disability counter-narrative will contest master narratives in its content. But it may also do so in its form, by enacting this principle that shape structures story. By writing a series of essays, I have attempted to allow shape (that is, my own and my son’s bodily selves) to structure my story. The repetitions, overlaps and gaps between essays reflect the repetitions and gaps in life with an autistic child. The fracturing of chronological development that occurs for a reader replicates the atypical developmental path followed by my son. Each essay includes a theoretical thread alongside stories about my life as a child and as a mother to suggest the complexity of the narrating self who is researcher, narrator, subject and parent of subject all at once. As Bynum says, we are ‘shapes with stories, always changing but also always carrying traces of what we were before’ (11). If ‘The present is only possible for us if it is framed and set off against a retained past and a potentially envisaged future’ (Carr 60), then it is not surprising I felt the need to write about my past as well as my possible future.

Susannah Mintz notes that the essay form is well suited to represent disability due to its resistance to closure and resolution and the way it evokes both unpredictability and the stasis of disability. In her analysis of Nancy Mairs’ essays, Mintz shows how the temporal looping across essays forestalls the reader’s ability to attain wholeness and continually forces the reader to question their understanding of disability. Graham Good, too, points out that ‘Instead of imposing a discursive order on experience, the essay lets its discourse take the shape of experience’ (7). He argues that the essay is unsystematic, spontaneous, opposes doctrines and cultivates diversity. And Gabrielle Carey notes that the personal essay is reflective, open-ended and oscillates between the public and the private, thus enabling it to address the complexities of subjectivity. As in memoir, the authority of the personal essay is not an authority of position or of learning but of personal experience. The truth

claimed is not a permanent, absolute truth but rather a temporary, personal and situated truth. The way the personal essay is resistant to closure, reflects unpredictability, is shaped by experience, fragments time, cultivates diversity, addresses subjectivity, and relies on the authority of personal and situated truth are all aspects contributing to the essay's value as form for telling counter-narratives.

As well as considering the form of my work, I was aware of the risk of adopting literary devices, particularly the use of metaphor. Knowing how often an autistic person is presented as fool, feral child, alien, genius or enigma, I looked for alternative metaphors. In the end, I found no alternative metaphor and came to the conclusion that this was appropriate, even if not aesthetically pleasing. It was interesting to then read Kristina Chew's analysis of autistic language and her conclusion that autistic people think metonymically rather than metaphorically.

I was also aware of trying to avoid the rhetorics of horror, triumph, spiritual compensation and nostalgia (Couser, *Conflicting Paradigms*), though I don't believe I always did so. In writing about a much-loved child, it is hard to avoid sentimentality, which allows the reader access to the narrator but lessens the characterisation. As Michael Ignatieff says (in the context of television and vulnerable subjects), 'Sentimental art sacrifices nuance, ambivalence, and complexity in favour of strong emotion' (293). As a parent, I wanted to express strong emotion but also wanted to embrace nuance, ambivalence and complexity.

It was difficult to use the rhetoric of emancipation that Couser calls for, perhaps because of a lack of models and perhaps because the very nature of a mother writing about her son works against this. I suspect that my son's own stories are more likely to exhibit emancipatory rhetoric, and that my role is to encourage and support him. I look forward to the time when I am no longer needed to speak for or with my son. As Michael Bérubé writes about his own son Jamie: 'For I have no sweeter dream than to imagine – aesthetically and ethically and parentally – that Jamie will someday be his own advocate, his own author, his own best representative' (*Life As We Know It* 264). In characterising my son, I tried to balance respect for his privacy with my desire to represent him as I perceived him. Because some of the essays were written when he was older, I was also able to include him beginning to question my interpretations, for example in 'The Shape of a Life' where he re-interprets my perspective on his interest in numbers.

Using the idea of parenting as cross-cultural translation helped me distinguish between representing difference and either erasing or domesticating it. I could write about my son's interest in drains and my own dismay about this without attempting to explain away his interest, present it as typical or judge it as invalid. Ironically, the more I felt I crossed the cultural border, the more I noticed my son's similarities to me, suggesting that he is a good border crosser too. While I am interested in and supportive of autistic culture, I have not followed Paradiž's lead in embracing it for myself or my son.³⁷ But I certainly don't feel any desire to normalise my son, either in life or narrative.

The 'between' where breakdown in translation occurs for Maier is reflected, I think, in my own work in both form and content. Like the other memoirs I analysed, my own work reflects the ambivalence and contradictions that parenting across difference often triggers. But I believe it is also characterised by an openness and self-reflexivity that reflects cross-cultural translation as process as well as product. The act of writing has been an act of research as creative practice.

I have argued that the parental memoirs discussed here act as a recuperative rite of passage to reincorporate the parent and child into society, either through a return to the mainstream (as in the cases of Maurice and Whelan), through an exploration or validation of difference within the mainstream (LaSalle and Collins) or through the embrace of autistic culture (Paradiž). My own sense of living in liminality has changed, too, as a result of writing my memoir. My reintegration, however, might be better expressed as a literary and scholarly recuperation. I have found a home among disability scholars and life writers as a researcher and practitioner. In daily life, my son and I are still marginalised, but in the life of the written word, I am not.

I recognise now that writing this work has been partly about better understanding my role as a parent, partly about creating a counter-narrative and partly about using narrative for social (or intellectual) reintegration. It is these very powerful motivations or benefits that have driven me to attempt to navigate my way through the ethical dilemmas of writing about my son. In spite of my exploration of other memoirs, of life writing scholarship and Disability Studies, and the production of this exegesis, my research has not meant that I have resolved the ethical, representational

³⁷ This might change as my son gets older and becomes more aware of the complexities around his differences from his peers.

or narrative challenges in my own memoir. Rather, I became more aware of these dilemmas and of my inability to satisfactorily resolve them. I recognise that my own limitations and perspective have both added value to and compromised my work. This, I think, is one of the most interesting aspects of relational memoirs and adds to the complexity of the ethical issues around such life writing.

The challenges of ethical representation and creating narrative are fundamental to life writing about disability and perhaps to any life writing where power inequalities exist. A parent writing about a child with a cognitive or developmental disability such as autism is surely one of the clearest cases where the two challenges are thrown into focus. While I have not resolved these challenges, I believe that any attempt to explore these issues – through scholarly or creative practice – is an important contribution to the fields of life writing and Disability Studies.

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