18q-, A Different Kind Of Normal:
Re-imagining Representation of Disability and Human Potentiality

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Statement of Original Authorship

The work contained in this thesis has not previously been submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made.

Signature:

Date:
Abstract

18q-: A Different Kind of Normal: Re-imagining Representation of Disability and Human Potentiality is a very personal project that evolved out of love and respect for those of us born with physical and intellectual impairment – made more precious when they happen to be our children. As a practice-led research project, a feature-length autobiographical documentary film has been created as a mechanism to explore the challenge of re-presenting the fullness of the lives of persons born with genetic difference on screen. The film introduces to the screen a group of individuals born with rare genetic conditions occurring on the 18th chromosome. It uses my family’s story as a vehicle to traverse the new and unknown terrain brought by intellectual and physical impairment. In a bid to usurp entrenched, stereotypical storytelling devices that continue to marginalise, demonise and dehumanise persons of difference, the film balances the sharing of challenges with the joy and delight expressed in our lives. As a mother, filmmaker, advocate, student, academic and subject within the film, I have charted my process within the exegesis and, in the absence of a formalised code of ethics for documentary filmmakers, I have explored ethical approaches across a number of disciplines in an endeavour to construct a framework to inform my work.
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Key Words

Advocacy
Autobiography
Bhaskar
Buber
Creative practice as research
Critical realism
Disability studies
Documentary and film ethics
Documentary film
Documentary theory and practice
Ethics of representation
Ethnography
Genetic
Medical model of disability
Pre-natal testing
Reflexive
Self-reflexive
Social model of disability
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This film is dedicated to those people born with differences on the 18th chromosome – the ways in which these differences manifest in the individuals affected by them are as a diverse as humanity itself. It is also dedicated to their families. I hope that I have captured some of the essence of our collective experiences by bringing the experiences of Allycia and our family, together with yours, to the screen and the page. Thank you to each of you who chose to entrust me with your stories – those that have made it to the screen and those that still remain unseen. I am honoured.

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Introduction

Everything starts as somebody's daydream. All people of action are first dreamers. The wonder of imagination is this: It has the power to light its own fire. Ability is a flame; creativity is a blaze. Originality sees things with fresh vision.

– Jhun Cunanan

18q-: A Different Kind of Normal: Re-imagining Representation of Disability and Human Potentiality is a very personal project that evolved out of love and respect for those of us born with physical and intellectual impairment – made more precious when they happen to be our children. Imagination and creativity become the tools with which we fashion our lives as we shed the burden of centuries of prejudice and challenge the limitations thrust upon us by medical diagnosis, while simultaneously embracing the healing brought by modern medicine. Our lives become more complex, yet are also made much more simple, as we navigate our way through new and old knowledge, piecing together new stories about ourselves for ourselves and relishing the accomplishments that most people take for granted. Simplicity arrives with the realisation that all is perfectly perfect in its seeming imperfection, for it is in difference that we find ourselves at peace, arriving at new understandings – just as it is the silence between the notes that creates melody.

18q-: A Different Kind of Normal, is a practice-based PhD comprising two elements: an autobiographical long-form documentary film and a written exegesis. For the work to be appreciated in its full context, viewing the film
would ideally be followed by reading the exegesis. However, each element has been constructed as a stand-alone work.

The source of my desire to create the film was twofold. First, I wanted to create a substantial filmic work addressing the genetic condition Chromosome 18q. When I began this work in 2005, audiovisual material addressing the condition did not exist – the project was intended to render the invisible, visible. The second was to create a piece that actively works against prevailing trends of representation of ‘the other’, specifically individuals and their families living with a disability. These portrayals, although increasingly contested as the collective voices of the disability community mobilise from within and bring their stories to a wider audience, continue to present the disability narrative as tragic, in need of repair and burdensome. This continued practice succeeds in marginalising, diminishing and silencing the lives of those living with intellectual and physical impairment (Barnes, 1992; Darke, 1999; Garland-Thomson, 2007; Mitchell and Snyder, 2001; Norden, 1994; Oliver, 1990; Shakespeare, 1996; Watermeyer, 2009).

The exegesis is concerned primarily with the documentary filmmaking process, and the theoretical, production, aesthetic and ethical considerations inherent in the making of a film within academic frameworks – particularly when embarking upon the sharing of narratives of people who may be described collectively as vulnerable. The process is further problematised due to the autobiographical nature of the work, wherein I – as filmmaker, student, citizen, mother and subsequently a person who now identifies as part of the disability
community – have been challenged to juggle the many competing voices and desires that have arisen during the making of the film.

The contribution to knowledge the film makes lays not so much in the realm of technical innovation or documentary filmmaking per se, but rather by way of the content and process. The individuals introduced in the film are ‘unknown’ in terms of their biological status and their lived experience to the general public, due to the rare occurrence of their condition. My exploration and fashioning of an ethical framework to guide my process may also be seen as a contribution to the field.

In terms of documentary theory and practice, the exegesis contributes to the ongoing discussion of autobiographical documentary filmmaking, the act of representation and the ensuing dilemma of ethical frameworks when working with a vulnerable group within an Australian tertiary context. A discussion addressing disability theory, representation and narrative is also included in the exegesis to provide a foundation and, in part, an explanation for the drive to produce this work. I believe the sharing of my experiences, confrontation with myself in the frame and the ethical issues I faced during the making of the film also contribute to the field of documentary theory and practice. I struggled with placing the personal alongside the public in an endeavour to educate and illuminate an audience who, in all likelihood, will have no first-hand experience of meeting a person with a Chromosome 18 anomaly.
In summary, the exegesis will discuss filmic representation of persons categorised as disabled and described as ‘othered’ in a Western cultural context, as well as the production of an autobiographical documentary film, and the ethical considerations that emerged while producing the work.

The primary audience for the film and that for the exegesis differ somewhat: the film is intended for those who have been given the diagnosis of a similar condition, members of the medical fraternity and the general public. The exegesis is primarily constructed for fellow filmmakers and students, medical students and scholars, with the intent of opening up new spaces for conversation amongst emerging practitioners regarding autobiographical documentary film and ethics, the diagnosis of genetic conditions with their accompanying treatment, delivery of information, and expectations about quality of life assertions regarding people born with genetic difference.

The work is interdisciplinary in nature and by necessity – indeed, the many disciplines underpinning disability studies demand this approach, and as such the foundational framework is grounded in Bhaskar’s critical realism (1998). One has only to glance through the extensive reference list cited by historian Catherine Kudlick (2003), who introduces disability as an historical subject and contextualises the analytical and theoretical precepts of disability as having their roots in anthropology as the fields that ‘blazed the trail for studying race, gender, and sexuality while introducing postmodernism and the linguistic turn’ (2003: 763). As this is a practice-based research project, the process of researching and examining theoretical frameworks inherent in filmmaking and
crafting a work that exemplifies engagement with the relevant frameworks has been one of trial and error, with a number of approaches having been taken during the course of the project. My greatest dilemma has been the balancing of my desire as a filmmaker to craft a piece that both embraces an audience and challenges entrenched ideologies about genetic difference, particularly intellectual impairment. While I am committed to contesting what I perceive as a collective devaluing of persons born with genetic difference, which increasingly has been affirmed in my research, finding a way to craft that contestation has been challenging. My hesitation in stating my own viewpoints via narration may leave an audience wondering exactly what it is I am trying to say. However, this is not necessarily a negative outcome, for the areas addressed by the film rarely deliver unequivocal answers to the issues raised. In bringing our community to the screen, I wanted to create a piece that would demonstrate the caring and supportive nature of our group in a bid to elevate how ‘we’ may be refigured. I have struggled with the drive to challenge notions of pre-natal testing and religiosity, while resisting falling into the dogma that exists on both sides of these debates.

With this multiplicity in formation, my hope is that the film will not only become a useful tool in the field of documentary film and practice, but that it may be of value – by way of the many issues raised in the work – in the fields of disability studies, social work, psychology, practice-led research, representation of the ‘other’, ethics, education, philosophy and emergent fields in biomedicine, including genetic counselling.
Background

Put bluntly, it is often not pragmatic for a disabled person to move, live and work in some environments, but it is valuable.

- Tanya Titchkosky

At the centre of this work is my daughter, Allycia. My intent is to deliver a gift to her in the form of a film honouring her and her peers, together with the many hands that uphold us. The gift is to offer an alternate reading of disability, a glimpse into the lives of people living with genetic difference. The intent is that, upon being given a diagnosis of the occurrence of an anomaly on the 18th chromosome, an individual or family will now have access to a personal account of what this term might come to mean, beyond the confines of medical laboratories, technical jargon and doctors’ surgeries. While the film addresses Chromosome 18q- specifically, the material in the film will resonate with others living with disability in that isolation and misinformation are common experiences. There is a desire and need to celebrate our sense of community and interdependence, along with the ability that exists in the disability community. My aim has been to create a work that will garner broadcaster attention in a bid to raise awareness of this particular condition, and to challenge misperceptions surrounding the oft-used ‘tragedy’ narrative associated with intellectual and physical impairment.

Allycia was born in 1995 with little incident until a short time after her birth, when she experienced severe cardiac failure. In her seventh month of life, she
underwent open-heart surgery to repair a congenital heart defect, mitral valve regurgitation. A year or so later, as I learned more about my daughter, I was advised that genetic testing may shed some light on the many different medical issues Allycia had experienced following her surgery. Allycia’s growth appeared to be impeded, her speech and cognitive development were substantially delayed, she was medicated for epilepsy and, as she grew, many of her physical features were ‘not quite normal’. The test results revealed that Allycia had been born with a rare genetic condition known then, in 1997, as Chromosome 18q23 deletion. I was told that part of her 18th chromosome was missing, and this deletion was the underlying cause of her development being significantly different from that of her older siblings, Adam and Kristina. The Chromosome 18 Registry and Research Society states:

> there are five major conditions involving large changes of the Chromosome 18. Each of these conditions has a wide variety of characteristics. Additionally, each of the conditions can vary in severity (2006: n.p)

This condition – now identifiable via new medical technologies that allow the examination of a person’s ‘genetic make-up’, which can classify human beings at a molecular level, is deemed rare and defines Allycia as being ‘other’ than ‘normal’. This new-found knowledge catapulted my family and me into a world that had become suddenly changed and unknown. Our address was the same but the way we viewed our once-familiar landscape was transformed. Doctors’ surgeries replaced playgrounds and hospital wards became a second home.
We were now ‘alone’ it seemed – the condition was rare. There was no one like ‘us’ around. I couldn’t find other people who had been born with this genetic condition. At that time, in 1996, I found a few photos and notes on the internet alerting me to some of the known medical facts about my daughter’s condition. From what I could ascertain, there wasn’t a great deal we could look forward to, but the text and the images did not resonate with the new little person that lay nestled in my arms. It would be ten years before we met other families with the same condition.

These experiences – the delivery of hard, cold, medical facts; the absence of others like us; the absence of stories or narratives that might have helped guide me, my family and the host of specialists and therapists who became a part of our everyday life; and our encounter with the ‘other’ and becoming ‘othered’ – were the impetus for this PhD work. I also became aware, over time, that medical statistics had begun to indicate corresponding increases in termination rates as genetically ‘othered’ foetuses were able to be identified via emergent pre-natal diagnosis technologies. I began to ponder what this trend said about ideas and beliefs surrounding people born with genetic difference, and how these decisions were being made, given the scant information available for prospective parents – and indeed medical professionals.

This ‘new’ place in which we found ourselves existed in a constant state of flux, with even the term ‘disability community’ at times seen as a contentious one. For example, Darke (1999), in his thesis addressing the ‘The Cinematic Construction of Physical Disability’ devotes approximately ten thousand words
to the discussion of the use of the words ‘disability’ and ‘impairment’, and the application of the Social Model of Disability versus the Medical Model of Disability within the context of his work. According to him, the Social Model denies that normality exists, but:

is a complex social construction that we use to make sense of the everyday.
As such, the Social Model theorists’ aim is to show that 'disability' does not exist as a reality and that it is merely a complex social construction of impairment as abnormality. (1999: n.p.)

Within a theoretical framework, this assertion may have resonance; however, within this work Allycia’s ‘othered’ physical and intellectual status is not at issue; rather, the focus lies in how this status impacts upon her life and that of our family. It is hoped that working through of the issues of representation of the ‘disabled’ ‘other’ will demonstrate that it is both unnecessary and counter-productive to collapse into either the Social or the Medical camp. Indeed, the World Health Organization (WHO) defines disabilities as:

an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. (2009: n.p.)

Further, the WHO states that ‘disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives’ (WHO, 2009: n.p.).
Given this complexity, I hope to produce a piece and invoke discussion reflecting Buber’s reasoning and work that focuses on the establishment of dialogue that lies somewhere in ‘between’, which explores the possibilities of emergent reciprocities and is responsive to the formation of both the ‘I’ and the ‘thou’ involved in the exchange of ideas. Buber’s discussion surrounding community as a possibility via the sharing of ideas that are responsive to historical moments in his address ‘Hope for the Hour’ is particularly pertinent, and could well be applied to an issue raised in both the film and the exegesis – pre-natal testing and genetic disability today:

The human world is today, as never before, split into two camps, each of which understands the other as the embodiment of falsehood and itself as the embodiment of truth … Each side has assumed monopoly of the sunlight and has plunged its antagonist into night, and each side demands that you decide between day and night … Expressed in modern terminology, he believes that he has ideas, his opponent only ideologies. This obsession feeds the mistrust that incites the two camps. (Buber, in Arnett, 1986: 28)

Here and now, in Allycia’s life and in mine, it would appear that past (medicalised) representations of people with disabilities continue to inform current ideologies and societal attitudes towards people born with genetic difference. While on the one hand a strong disability movement has been taking steps towards being heard and seen in a different light, writers such as Goggin (2002) express concern at another movement that is gaining momentum:
the eugenicist imperative in late modernity has been transmogrified into a variety of practices which seek to ‘eliminate’ the birthing of bodies marked as ‘disabled’ or, in the event of our/their postnatal ‘existence’ to engage ‘perfecting’ technologies that morph ableism and enshrine a particular understanding of ableist normativity and (real) human subjectivity (2002: 266).

As technological developments herald the hope of a more perfect humanity and ensure greater quality of life and longevity (Allycia’s potentially fatal heart condition was repaired due to medical advances), these developments have also provided and continue to explore more sophisticated mechanisms for and means of terminating life. As these technologies progress and statistics reveal corresponding increases in termination rates directly associated with genetic analysis, the need for furnishing alternate narratives and the re-imagining of life with disability is essential if truly informed decisions are to be made about the future births of people of difference.

The need for more widespread stories and narratives concerning people living with disability has been reflected in academic critiquing of films concerning disability, as well as in studies directly addressing audience members of the disability community. A journal article I came across early in my research reviewed two documentary works, the US work *Family Challenges: Parenting with a Disability* (1998) and the Australian-made film *Belinda’s Baby* (1997). The US film charts the lives of three families living with disability in various contexts, highlighted the hardships and sadness of the families where a parent with a disability was present. *Belinda’s Baby* demonstrates Belinda’s (a disability advocate who lives with muscular dystrophy) strength of character.
when she and her husband decide to become parents against medical advice. However, the lack of support, helping hands and friendship in Belinda’s life seems to overshadow the joy and triumph of parenthood. There can be no denying that living with disability presents challenges that may not be faced by the greater population, but the works did little to inspire others with disability to become parents, failing to balance the challenges sufficiently, with only a small portion of each film being devoted to sharing the good times. The writer’s disappointment with the content and the approaches adopted in the films prompted a call for ‘unusual, practical, humorous and/or helpful films on parenting with a disability’ (Duncan, 2001).

In his qualitative audience study regarding disability representation in film and television, Velez (2008) found that audience members identifying as having a disability were keen to see ‘a more restrained aesthetic and rhetorical position on the part of film producers, which will help turn attention away from bodily difference and on to traits most people share’ (2008: 237). I have kept this call in mind as I have fashioned this film.

In concluding this brief backgrounding of the work, I would like to draw attention to the title of the exegesis and the notion of re-imagining human potentiality in the context of this work. It not only encompasses the re-imagining of the lives of persons born with genetic difference, but also invokes the potentiality of persons characterised with an able body and mind. For it is we so-called ‘normal’, average people who will, in part, navigate and define a future for those born of difference, and in doing so we too may be called to re-
imagine how our lives are lived. As Marsha Saxton, a disability activist born with spina bifida, puts it:

The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are "too flawed" at our very DNA core to exist, unworthy of being born. This message is painful to confront. It seems tempting to take on easier battles or even just to give in. But fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and equality: We are indeed worthy of being born, we are worth the help and expense, and we know it! (1998: 391)

In short, I hope the work progresses attitudes about living with genetic disability, and that in sharing our stories, we as a community will demonstrate that we live full and fruitful lives and we are worth it.
The Exegesis

Chapter 1 establishes the frameworks used to create the film and complete the exegesis via the literature review. The literature review includes literary references as well as outlining the films, both fiction and documentary, that have impacted significantly upon me as a researcher, audience member and filmmaker. As an audience member, drama paved the way for me to re-imagine the way in which we might live our lives as members of a family with a person deemed disabled. Here I wish to emphasise the importance and value of fictional film dealing with disability in furnishing unimagined possibilities for those with disability, in light of the fact that positive narratives in the dramatic and documentary realms have been almost absent (Barnes, 1992; Darke, 1999; Garland-Thomson, 2007; Mitchell and Snyder, 2001; Norden, 1994; Oliver, 1990; Shakespeare, 1996; Watermeyer, 2009). As a filmmaker, a number of documentary films and filmmakers – not necessarily concerning disability – have played an important role in shaping the structure of, and my approach to, the completed film.

Disability theory and the recurring debate regarding media representation of those with disability will be reviewed, as will those texts that were most influential in terms of crafting the narrative of the film from an autobiographical perspective. To a lesser degree, I will review audience reception theory in terms of the potential a proliferation of changing imagery may have to challenge dominant discourses associated with living with disability.
Key documentary theorists will be identified in the literature review in a bid to contextualise the production of *18q*: A Different Kind of Normal as an autobiographical documentary in a contemporary setting, and in a sense justify the intent and the construction of the piece. Within the literature review, I establish the theoretical framework of Bhaskar’s Critical Realism (CR) as the foundation of my methodology, together with various other research paradigms embraced during the course of making the film and writing the exegesis, which are further explicated in Chapter 2.

Chapter 3 outlines key disability theorists whose research has established the historical routes of disability representation, and grounds the work in academic theoretical approaches. Disability theory, the nature of autobiography, representation and narrative are explored as ways of revealing my process, my desire to present a re-imagining of both persons of genetic difference and my own life following Allycia’s dismal initial prognosis, and those writers whose influence has played a significant part in shaping the final piece. Within the critique of representation of persons living with disability is a torrent of disdain for the way in which the supposed tragic ‘other’, with their frailty, is despised for their helplessness and the burden they lay upon those around them who become their carers. As well, the heroic depictions of those strong and brave enough to overcome their afflictions with the help of heroic able-bodied persons – the ‘good and kind’ people who take up the burden – are scrutinised.

By exploring the categorisation of people as disabled – specifically those born with intellectual and physical difference due to genetic factors – my motivation
for making the film is clarified further in a bid to contextualise the film within current representational modes. The chapter also focuses on the importance of narrative and the telling of stories in terms of carving a place for those living with difference in a world where difference is seen as deviant and undesirable.

The chapter serves as a foundation to background the approaches taken in the film, which will be discussed in Chapter 4. Here, influential works and filmmakers will be introduced – particularly in the field of the new documentary – with particular attention given to the production and editing processes, and to the ethical challenges arising during these processes.

Chapter 4 takes up these ethical challenges, exploring them further from both a personal and professional perspective, and attempts to lay bare the difficult terrain that is travelled when bringing the personal lives of friends and family to the screen, as well as the delicate balance one faces as an advocate for people whose position in life may be viewed as vulnerable due to intellectual impairment.

In concluding the exegesis, I bring together my personal experience and current theoretical approaches to autobiographical documentary filmmaking and disability studies. I revisit some of the key issues I believe are impacting upon those born with disability, together with the need to continue to create works – and indeed bring together a ‘library of sorts’ of the lived experiences of those born with disability and their families. Such a library would be accessed primarily by medical practitioners, educators, law-makers and, most
importantly, prospective parents when pre-natal diagnoses indicate that genetic differences are present in their unborn children. Effective informed decisions can only be made when information is imparted, and it is my contention that without a library of alternate narratives and the opportunity to ‘meet’ people of difference onscreen – or preferably in person – such decisions are not really possible. The re-imagining of disability needs to be re-presented to a society whose ideas and beliefs have been (mis)shaped by outdated and inaccurate narratives of times long past.

My hope for this film is that a glimpse into our life – one that is filled with myriad experiences, flawed at times, questioning, searching, involving a thirst for knowledge – will inspire hope and a deep respect for those ‘others’ in our community.
As part of a practice-based research project, this exegesis recounts my engagement with a number of theoretical frameworks underpinning disability studies and representation as the impetus for creating an autobiographical documentary film introducing a rare chromosomal condition. My intention was to produce an autobiographical documentary film challenging prevailing perceptions about how lives may be lived with a genetic anomaly that results in physical and intellectual impairment. Consequently, the texts I have reviewed are diverse – largely due to the multi-disciplinary nature of inquiry, and the fact that academic interest has begun to turn to the examination of disability, autobiography and filmmaking. When I began this project, there was no significant audio-visual work available for public distribution that represented those living with Chromosome 18 conditions, and very few academic texts that reflected upon the making of autobiographical documentary films. To my knowledge, at the time of completion this is still the only work of its kind, whereby a film accompanied by an exegesis examining process and form has been made within an academic environment by a parent about their child born with a rare genetic condition. The project – the sharing of my experiences and challenges in creating the work – thus may be seen as a timely critique, as the widespread use of home video and of the capacity to distribute works via the internet have spawned the video diary and the sharing of parents’ stories about their lives with their children with disability. Is there a preferred way of telling our stories? What ethical frameworks should be employed during pre-
production, production and post-production? And how many levels of risk are associated with such an endeavour? These are some of the questions with which I grappled, due to the lack of critique and formalised frameworks currently available to assist with such an endeavour.

Examining a diverse array of texts in a bid to flesh out an appropriate approach, style and methodology meant becoming, as Robyn Stewart (2000: n.p.) describes it, a ‘bricoleur’ of sorts, appropriating ‘available methods, strategies and empirical materials’ and piecing ‘together new tools as necessary’. Contesting prevalent modes of representation of people living with disability first demanded reflection about how the construct of disability had emerged over time. This line of inquiry was in fact a questioning of self, due to my own realisations about a number of ideas I had about disability and the way those ideas were contested at the most intimate of interfaces – that between mother and child. My initial expectations about my daughter’s capacity to learn and the quality of life she would enjoy were shaped by both the medical prognosis (stories) I was given and my preconceived ideas, which had been shaped as a child when ‘spastics’ and ‘retards’ were not seen in mainstream schools and were confined to institutional living as adults.

Following this logic, Burnett’s work in formulating a ‘coherent guiding philosophy’ (2007: 1) as a means for progressing current special education versus inclusion arguments regarding children with disability and access to appropriate education resonated with my experience as a parent within the education sector, as well as some of my encounters with some specialists in
the medical arena. Burnett had adopted Bhaskar’s (1978, 1989) rubric of Critical Realism (CR) as a means of establishing this guiding philosophy, and it was in Bhaskar’s words that I saw the intent of my project reflected: ‘the world cannot be rationally changed unless it is adequately interpreted’ (1998: 5).

Burnett’s interpretation and extension of Bhaskar’s precepts of the intransitive and the transitive to explore the possible dynamics underlying relationships between special education teachers and parents of children with disability played a significant role in my theoretical process. Burnett places the interplay between teacher and parent – the unspoken but ever-present power relations that exist between the teacher as expert and the parent as lay person – as existing in the intransitive dimension, or as ‘the real things and structures, mechanisms and processes, events and possibilities of the world’, which are ‘quite independent of us’ (Bhaskar, in Burnett, 2007: 2). In so doing, Burnett illustrates the impact of the cultural constructs within which exchanges about disability take place, and draws attention to the idea that those involved in these encounters are often not consciously aware of those ‘unseen’ elements. This description resonated with my experiences with educators, and with many encounters I’d had with medical experts wherein at the beginning of Allycia’s life I submitted to the expert opinions about the disabled, believing that those invested with prior knowledge knew more about my daughter than I did.

Burnett illustrates the potentiality of Bhaskar’s transitive dimension as the capacity for those involved in these encounters to gain new knowledge and awareness of the intransitive dimensions – those previously entrenched
positions, values and beliefs that are held; once this occurs, change is possible. As I began to understand that those experts charged with directing our paths were working within broader medicalised definitions of what being disabled meant, I realised that the new knowledge I was gaining through my interactions with my daughter was just as valuable as the experts’ claims to knowledge.

The CR approach to identifying ontological and epistemological premises avoids the assignation of broad characteristics to a group or setting, and the individuals in that group or setting, and involves a search for underlying mechanisms which may or may not be at play in other situations (Burnett, 2007). This approach offered a broad theoretical framework for describing my experiences within both the film and the exegesis. Burnett’s assertion that the CR view gives rise to the ‘opportunity for individuals to impact on society while recognising the impact society does have on individuals’ has currency in the potential of the film and exegesis as ‘transformational social activity’ (2007: 3).

Progressing the project meant engagement with the literature describing Allycia’s condition in medicalised terms, and involved placing those findings against texts now comprising the broader set of disability studies, exploring the social model of disability in its many contexts. Assessing these texts alongside Allycia’s and our lived experiences, together with those of other individuals and families living with Chromosome 18 anomalies, followed. This approach enabled me begin to ‘see’ the medical and social models of disability in a different light, and thus to engage in the theory and practice of making the film.
This model was not necessarily unique, and as I was formulating my process, Childress (2008: 5–28) was working in a parallel field, constructing a framework for biographical documentary film based upon CR philosophy that reflected some of the practices and processes in which I was engaging. Interestingly, while his work concerned a process for documenting the assassination of Rwandan President Juvenal Habyarimana, he likens the process to that of scientific inquiry surrounding chromosomes:

Thus when the documentary filmmaker simply renders an object or event visible, as the chromosome is rendered visible by the microscope, production of a concept is missing and a qualitative description of the object (the biographical subject and its interrelatedness to structures) is incomplete. (2008: 19–20)

Moving beyond simply rendering an object or event visible, Childress works towards showing the biographical subject as ‘connected outside as well as inside their time, and in relation to different levels of agency in the context of their culture’ (2008: 5). Childress’s proximity to the subject-matter he explores is somewhat more distanced than mine, due to the autobiographical nature of my work; however, the framework and theoretical approach allowed me to step ‘outside’ myself and my circumstances to a degree (as much as is possible in a creating a work about oneself, by oneself) and view both the work and myself as existing within the flux of what we describe as culture.

Defining culture is a difficult and complex task, and in the context of disability studies worthy of much discussion, though it is not a central concern of this
exegesis per se. However, I am working on the basis of certain assumptions about the culture within which I and my family exist in a modern, Western, urbanised environment. The film is constructed within this environment, and is an artefact born of, and driven by, what I have identified as ‘silence’ in reference to our Chromosome 18 community. Hinde’s notion of culture being ‘used in a sense, to refer to the artefacts, customs, institutions, myths etc as described by an outsider (or indeed by a member of the society)’ (1987: 4) lends itself well to this project. Further, culture is ‘best viewed as existing in the minds (separately or collectively) of the individuals of the society as a continuous process of creation through the activities of individuals in their relationships’ (1987: 4). This project reflects such a description, as my family and I, together with other members of the Chromosome 18 community, contest notions of ‘normality’ and ‘quality of life’ within the culture of which we are a part, and demonstrate the capacity for renegotiating these cultural definitions, showing that we have shifted somewhat ‘outside’ our primary societal membership.

The film also brings to life the call from Dr Jani Klotz (2003) for:

ethnographic accounts that give priority to the lived experience and negotiated meaning of “disability” in whatever form these become manifest. Through such multivariated approaches to the use of culture as an analytical tool, and by juggling the concept of culture as something which we both inherit and create, anthropologists are in a position to both critique and enhance our understanding of disability as a complex social, cultural and biomedical phenomenon. (2003: 24)
This critiquing and enhancing of disability and its complexity is achieved in the film by challenging the text-based medical stories with the living breathing manifestation of the individuals being portrayed, described thus:

Chromosome 18q- syndrome (also known as Chromosome 18, Monosomy 18q) is a rare chromosomal disorder in which there is deletion of part of the long arm (q) of Chromosome 18. Associated symptoms and findings may vary greatly in range and severity from case to case. However, characteristic features include short stature; mental retardation; poor muscle tone (hypotonia); malformations of the hands and feet; and abnormalities of the skull and facial (craniofacial) region, such as a small head (microcephaly), a "carp-shaped" mouth, deeply set eyes, prominent ears, and/or unusually flat, underdeveloped midfacial regions (midfacial hypoplasia). Some affected individuals may also have visual abnormalities, hearing impairment, genital malformations, structural heart defects, and/or other physical abnormalities. Chromosome 18q- syndrome usually appears to result from spontaneous (de novo) errors very early during embryonic development that occur for unknown reasons (sporadically). (2003: 67–9)

This medical story, nuanced with medical jargon, risk implications and projected outcomes – distanced, impersonal and devoid of emotion – encapsulates the medical model with which social model theorists have taken issue. There is neither recognition of personage nor societal implications in the volume. The text constitutes and evidences the limitations of the medical model in the individual identity of persons born with anomalies occurring on the 18th chromosome. The social model, which began with the work of Oliver (1990), Barnes (1992) and Shakespeare (1996), takes further issue with the medical model as situating the problem of disability within the individual, and
places the ‘problem’ of disability squarely with the disabling practices of the society and culture within which persons with physical and intellectual impairment exist. My experiences had led me to the belief that both viewpoints contained certain ‘truths’, but that our lived experience seemed to sit somewhere in between. This was the essence of what I hoped to capture in the film – I was in fact seeking a different way of representing disability.

Longmore (1987), Darke (1999), Snyder and Mitchell (2001), Mitchell and Snyder (2000) and Australians Goggin and Newell (2005) and Campbell (2008, 2009), amongst many others, provide extensive examinations of how disability has been represented in texts and the arts over time. Norden’s (1994) research also highlights the stereotypical portrayals of disability as pitiful, in need of repair, monstrous and inhuman, whereby the historical representation of disability in Western narrative film has been used as a device to shape stories of isolation, sorrow and pity, coupled with the quest to overcome disability in a bid to become normal. I found that these works highlighted the shortcomings of the works in the past, but they did not necessarily articulate concrete ways for me to move forwards in constructing my film. Ellis’s examination of the social construction of disability in Australian national cinema (2004) offered some emergent fictional works as being examples of best practice in Australian fictional film; however, the issues with which I was concerned were not those that works such as Thunderstruck (2004) and Under the Radar (2004) tackled in a fictional context.
Disability theorists assert that these constructions are perpetuated not only in fiction, but also in media coverage and the documentary form. In her examination of disability in contemporary Australian current affairs programming, Symonds (2006: 157–70) signifies the continued perpetuation of problematic image-making and storytelling devices, which serve to further entrench perceptions of inability and burden associated with disability. Duncan’s (2001) review of the shortcomings in documentary work associated with parenting and disability provides some clues for finding new ways of bringing our stories forth, specifically in her call for ‘unusual, practical, humorous and/or helpful films on parenting with a disability’. Further complicating her call and direction for me, however, was the project of putting together a piece that was so very close to home; while I believe that we, as parents, are the people best placed to share our experiences, creating a film marking our experiences was always going to be a difficult endeavour, due to the close proximity of myself as filmmaker to the subject-matter and those who bring it life on a daily basis.

The competing disability narrative has been represented strongly in autobiographical works; however, the validity and value of individuals’ life stories – those of the solitary voice – has not been uncontested in terms of the danger of the autobiography falling into the stereotypical trope of the heroic overcoming of disability. Mitchell raises concerns that the privileging of the one voice in autobiography fails to embrace communal identity of disability (2000: 312). Hardwig (1997), too, raises concerns that for a full or ‘true’ biography, biographies of family members and friends may be needed to verify an
individual’s claims to truth. In answer to these issues, 18q: A Different Kind of Normal includes members of the Chromosome 18 community, whose experiences – while similar – differ substantially from one another. In addition, I have included our family’s perspectives as a means of verifying our experiences.

Linton’s My Body Politic (2007) and McHenry’s (2007) work introduced the pervasive narrative of the so-called body perfect (ableist) as the competing narrative to the acceptance and embracing of disability as a valid state of being. As a means of contesting the ableist perspective, Rick Guidotti and his work with the Positive Exposure project – which ‘challenges the stigma associated with difference by celebrating the beauty of human diversity’ (2008) – are featured in my film, serving to challenge culturally constructed ideologies of physical beauty.

In navigating my path from the theoretical to the practical, I found film theory needed to be addressed, with particular attention given to the creation of autobiographical documentary films. This avenue of inquiry also embraced issues of representation and narrative – how our stories might be told. Garland-Thomson’s ‘shape structuring story’ (2007:14) was used as a starting point for discussion, paving the way for elucidating further the notion of narrative within autobiographical practice. The absence of narrative noted in Smith and Sparkes’ call for ‘stocks of narrative’ (2008: 19), wherein the majority of available narratives for people of genetic difference abide in the
medical realm and continue to be told in the absence of chronicled lived experience, signalled the contribution my film would make to these stocks.

In charting the actual production of the work, I drew upon the frameworks used within documentary theory and practice as the foundation for praxis, with my accompanying reflections concerning key influences in terms of approach and aesthetics. Seminal documentary texts by Nichols (1991) and Winston (1995) were the historical building blocks, built upon by the work of Rabiger (1998), Bruzzi (2000), Renov (2004), Williams (2005) and Bernard (2007) to inform the work. With Rabiger’s ‘how to’ in directing documentary and the progressive evolution of the form documented by Bruzzi, Renov, Williams and Bernard, process and form started to take on a physical shape as I began to marry the theory with practice. The later works advocated the value of the new documentary form, whereby the subjective view increasingly was becoming a recognised and valid approach; hence I reviewed numerous documentary films within the emergent autobiographical mode, with McElwee’s Sherman’s March (see McElwee, 1998) being of particular significance in his construction of self. Rabiger’s description of McElwee’s characterisation within his works as that of ‘everyman’ (1998: 336) would become one of ‘everywoman’ in my case, as I endeavoured to characterise myself within my own film, exposing my shortcomings and misconceptions as a means of usurping the previous ‘heroic’ constructions within the disability narrative and endeavouring to connect with an audience previously unfamiliar with disability.
Had I simply been charting my own shortcomings without implicating my family and our Chromosome 18 community, addressing the ethics of bringing my own life to view for public consumption may not have been so necessary, exhaustive or arduous. However, as discussed by Nichols (1991) and Winston (1995), the ethics of representation can become quite complex, depending upon a number of factors, particularly who might constitute the subjects of the work. The issues raised by Nichols and Winston were made more complex due to the nature of my project, which involved family and persons with varying intellectual capacities. I turned to Katz’s (2000) critique, ‘Family Film: Ethical Implications for Consent’, examining Ira Wohl’s biographical documentary films about his cousin Philly Wohl, who is affected by intellectual impairment (Gross et al 2003: 327–43). In exploring the content, approach and outcomes of Ira Wohl’s award-winning films, Katz highlights those interventions on the filmmaker’s part that had the potential of placing the subject of the film, Philly, at risk. Katz also questions the notion of obtaining Philly’s consent to create the work, given Philly’s differing intellectual capacity for understanding the implications of making his private life public. The ethical considerations brought to bear in this discussion went quite some way towards furthering my framework for the film; however, as the parent of a person who is subject to my consent, my position again engendered further complexity.

Without access to any similar work to mine, and in the absence of formalised ethical frameworks for documentary film in general – and my project in particular – I turned to Couser’s (2004) critique of Dorris’s autobiographical memoir, The Broken Cord (1982). The risks involved in representing one’s
child whose life is affected by intellectual impairment are articulated clearly in Couser’s work, and serve to mark several contentious areas that reflect the value of exploring a CR approach to the work of autobiography in this context. In Couser’s challenge to the notion of informed consent, he signals the need for caution in obtaining such consent from a person whose intellectual capacity is compromised; the situation is complicated further by the close proximity and ensuing power relations present in the relationship between Dorris and his son. Of equal concern to Couser was the structure of the work when it came to addressing Dorris’s son’s condition, which was the result of foetal alcohol syndrome. In Couser’s opinion, the failure of Dorris to engage in the wider societal and cultural environments relating to the occurrence of foetal alcohol syndrome within Native American communities succeeded in echoing, rather than revising, ‘traditional inscriptions of race and disability’ (2004: 72).

By identifying the potential ethical dilemmas inherent in the work, my task became one of finding models that offered aspects of what was required, and that could be assessed and justified via an interrogation informed by the tenets of the CR approach. Blackall’s (1999) work on the Australian broadcast media industry, and his subsequent production of a biographical documentary film that brought to bear on a number of unique ethical challenges the frameworks articulated by aforementioned documentary theorist Ruby (1980) and Martin’s suggested methodology for becoming a ‘knowing bioethicist’ (1999: 316–27) were to provide the guiding principles for the way I approached the subjects of my film and the content of my exegesis.
In concluding the exegesis, and bringing together the experiential and the theoretical, I offer my work as a place to proceed from and build upon for the future in bringing the stories of those within our society who are living with disability – particularly intellectual disability – to the attention of a wider public, and by doing so to enact one of the aims of Critical Realist philosophy by engaging in our storytelling as a potentially transformational social activity.
2

Methodology

In the creative process, the most meaningful insights often come by surprise, and unexpectedly, and even against the will of the creator.

- McNiff (2008: 40)

As a practice-based research project, *18q*: A Different Kind of Normal – both the exegesis and the production of the documentary – embraces a bricolage of research traditions and methodologies, ‘drawing upon a number of interpretative paradigms’ (Stewart, 2000: n.p.) in presenting multiple counter-narratives to the entrenched, pervasive, medicalised and stigmatised narratives of ‘the genetic other’ in documentary film and television broadcasts.

The project is intimately concerned with the disabled ‘other’, situated within disability studies and steeped in the concepts of anthropological studies. As an autobiographical work, the production of the film and subsequent exegesis also embrace Stewart’s ‘personal investigation of the self: self-research self-portrait; self-narrative’ (2000: n.p.).

With the complexity of the work apparent, approaching the work from a Critical Realism (CR) perspective appeared to offer a way through. CR, a philosophy of science, emerging from the work of Roy Bhaskar in his *A Realist Theory of Science* (1978) and further developed by Bhaskar and other theorists including Archer and Collier (1998) is complex in its exploration and interrogation of theoretical precepts and historical standpoints, with a full and comprehensive
account being beyond the scope of this thesis. In its most basic form it may be said that Bhaskar drew ideas from scientific realism in a bid to critique the then current positivist and hermeneutical modes of social sciences and offer alternatives to those modes. In Archer and Bhaskar’s words:

> grounds for abstraction lie in the real stratification (and ontological depth) of nature and society. They are not subjective classifications of an undifferentiated empirical reality, but attempts to grasp (for example in real definitions of social life already understood in a pre-scientific way) precisely the generative mechanisms and causal structures which account in all their complex and multiple determinations for the concrete phenomena of human history (2009: xvi)

As a philosophy CR is indeed complex, however it was the practical application of the approach that appealed to me and offered the bridge between the ontological and epistemological I was looking for. Bhaskar’s notion of the stratified nature of reality with an emphasis upon contextuality and the critical relationships between structure and agency (1978: 56) seemed an appropriate “fit” for the research. The application of CR in the work of Danermark (2002) in the fields of interdisciplinarity and disability research and that of Childress (2008) in the realm of biographical film making were particularly pertinent within the scope of my work.

Analysis of the medical and social models of disability using a CR based framework (as demonstrated in Danermark’s work (2002)) and as a means to craft a framework for self reflection provided critical reference points and concrete examples of how CR could be adopted in my approach. Steven Childress’ (2008) visual representations of interpretative paradigms presented
in his work concerning the crafting of a biographical documentary about Rwanda’s assassinated president Juvenal Habyarimana provided a ‘roadmap’ of sorts for the process.

I have perhaps ‘stepped back in time’, drawing upon Bell’s (2004) call to diminish the divide between film theory and practice, as well as reuniting practice-based research and bringing ‘the rigour of critical theory to the core of the creative process, hopefully illuminating our work and our teaching but also testing the precepts of criticism and grounding film and media theoretical abstractions in our creative engagements’ (2004: 738). Within this tenure, the research can be more clearly seen as grounded in Bhaskar’s CR, as described by Burnett, who posits ontology as ‘being identified as the “world as it is” and epistemology as the “world as we know it” or in other words our “knowledge” of it’ (Collier, 1994, in Burnett, 2007: n.p.).

This description resonated for me with the descriptors of the medical and social models of disability, in which Chromosome 18 anomalies sit within the ontological; and where the world as we once knew it has been changed or transformed as a result of emergent ‘knowns and unknowns’ that may be seen as the epistemological counterpart. The film and praxis have been designed to reflect Burnett’s assertions that ‘individuals both reproduce and transform social structures as well as are formed by them, while social structures both shape and place constraints on individuals but are also the result of continuous activity by individuals’ (2007: 7).
Figure 2.1 demonstrates the theoretical practice domain; however, in Figure 2.2 I have substituted the Biological for the Philosophical, in keeping with the social versus medical models. This is due to my not contesting Allycia’s or her peers’ biological status – in this historical moment, the molecular structure of the chromosome is an anomaly, is unchangeable and has resulted in particular physical and intellectual manifestations.

Source: Childress (2008: 6).

Figure 2.1: Critical Realist scientific practice (after Ardebili)
Figure 2.2: Modified Critical Realist scientific practice (after Ardebili)

Source: Childress (2008: 6).

Figure 2.3: Domains of reality

Source: Childress (2008: 11).
I used these two figures as referents for the ways in which the themes in the film have been defined and refined (see Figure 2.4).

<table>
<thead>
<tr>
<th>Empirical</th>
<th>Empirical facts</th>
<th>The images captured in the film</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual</td>
<td>Factual events</td>
<td>The intransient – largely unobservable – social mores, cultural ideas (narration, spoken and written texts) Also may be visual referent – the chromosome animation represents actual and real</td>
</tr>
<tr>
<td>Real</td>
<td>Mechanisms</td>
<td>Outlined in the following diagram</td>
</tr>
</tbody>
</table>

**Figure 2.4: Domains of reality in the film 18q: A Different Kind of Normal**

Moving from this overview to the construct in Figure 2.5, the film and the exegesis demonstrate the interplay of the structural tiers and way in which, with shifts in one tier of the construct, the effects can succeed in shifting those above. One theme central to the work is the re-imagining of life following the delivery of a genetic anomaly diagnosis.
Figure 2.5: The stratified nature of reality

This model has also assisted me to unpack the social and medical models in terms of a research framework to contest the polarised views each represents, and to attempt to show the ‘in between’. However, it has been our progressive discovery of a wider community and new knowledge that has facilitated an upward conflation. For example, in the film I have constructed the narrative to demonstrate my changing attitudes over time. My initial reaction to Allycia’s status was a sense that my life was over, and that we were alone. As the film progresses, the audience becomes privy to my growing interest in film, Allycia’s love of dance, the discovery of a new community and the delight of our journey together to the United States to meet the international Chromosome-18 community. In presenting our particular journey, we meet others whose movement from the fundamentally restrictive biological diagnosis scenario towards their own self-discovery and current entrenched ideologies of the disabled means their initial expectations are challenged.
With this approach in mind, I determined that a discussion of disability theory, narrative, representation and autobiography would be necessary: if I was to succeed in demonstrating significant transformative moments, events and actions, I would need to show from whence we came. With this approach, I believed I would be better able to illustrate the various events that have reshaped my perceptions in the film, and within the exegesis, demonstrate how a critical realist approach enhanced the final production.

It is important to note that I have not taken issue with the molecular structure of the condition categorised as 18q-. Whatever we might choose to call ‘it’, the condition and its manifestations in the physical sit outside a ‘median of sorts’ that has been defined within the field of genetics as ‘normal’. Certainly in our lives, most of us do not live with epilepsy, nor do we require heart surgery as an infant. Allycia’s body – including her genetic code and its effects on and within her body – has significantly impacted upon her life. These manifestations would have occurred whether or not she was coded as normal or abnormal. However, what is at stake here – where there has been a necessity to ‘sit in between’ the medical and the social models, resonating within a Critical Realist approach – is the manner in which information about the condition has been communicated, and subsequent engagements with the world as it is, as it was and how we have determined to make it as we move forward into the future.

I demonstrate the relationship between the ontological and the epistemological, presenting the potentiality for significant attitudinal change regarding how the
category of disability may be viewed and redetermined. By presenting current work in disability studies, I bring forth some of the tensions and gaps between the medical and social models, and demonstrate some of the weaknesses in current endeavours to further critical work in the field, such as informed policy formulation. The inclusion of narrative, representation and autobiography in this work furthers the discussion and illustrates Garland-Thomson’s ‘shape structuring story’ (2007: 114) by providing a visual account of the way that: ‘Narratives do cultural work. They frame our understandings of raw, unorganized experience, giving it coherent meaning and making it accessible to us through story’ (2007: 122).

The coupling of the continued activity of individuals either conforming to, or contesting, prevalent modes of representation in the film blurs the lines between the able and the disabled experience, illustrating the impact, capacity and potentiality of human action and reaction upon the visible and invisible structures that historically have shaped our stories.

Grounded theory frameworks were considered, particularly in light of Blackall’s (2004) extensive work in developing ethical frameworks during the course of his practice-based PhD, where he created a documentary film concerning Australian painter John Perceval. These perspectives were useful; however, due to the close familial relationships involved in my work, the autobiographical approach and the desire to include a significant level of self-reflection, CR seemed a better fit for the task at hand, allowing the personal to be more fully included in the process and given the fact that I was working from a pre-
conceived theoretical position, rather than looking to necessarily formulate a new one. However, as discussed in Chapter 4, my eventual crafting of an ethical approach based upon Martin’s (1999) work in the medical field and of becoming a ‘knowing bioethicist’ may be viewed as embracing and working within grounded theory; here, I have explored several other ethical approaches, which eventuated in the formulation of a new, more extensive ethical framework.

I have accessed quantitative and qualitative works in the medical field to establish the basis for my concern regarding predictive pre-natal technologies and the growing body of evidence indicating an increase in termination rates due to ‘defective’ analyses being delivered to prospective parents. This research is included as justification of sorts for what I propose as a need to provide alternate narratives about living with disability – or, as articulated in my paper ‘A Valuable Life: Reterritorializing Genetic Disability in Australia & the Documentary 18q’ (Wain, 2008), Deleuze and Guattari’s (1987) context of alternate lines of flight. While the work is driven by a strong personal motivation to raise awareness of this issue, Chromosome 18 anomalies and a belief in the need for a re-presentation of people with disability that has in part been supported by other academic documentation, the film or cultural product is constructed within the world of documentary filmmaking.

The film embraces aspects of traditional forms of documentary described by Nichols (1991), namely the observational, expositional, interactive and reflexive modes. Further to adopting these approaches, the film may be
categorised as Renov’s ‘domestic ethnography’ (2004: 216), described as the ‘documentation of family members or, less literally, of people with whom the maker has maintained long-standing everyday relations and has thus achieved a level of casual intimacy’ (2004: 218). The autobiographical approach to the work further complicates the project by necessitating the construction of a framework for the telling of my part of the Chromosome 18 story and reflecting upon my process. To this end, I have turned to a phenomenological approach, which:

may be defined initially as the study of structures of experience, or consciousness. Literally, phenomenology is the study of phenomena: appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience. (Smith, 2003, n.p.)

Further, given the ethical considerations and implications of the work in terms of the treatment and representation of those individuals within the film and the place the work will occupy within documentary theory and practice, the field of phenomenology was also a useful framework to inform the work, being:

distinguished from, and related to, the other main fields of philosophy: (the study of being or what is), epistemology (the study of knowledge), logic (the study of valid reasoning), ethics (the study of right and wrong action), etc. (Smith 2003, n.p.)

Embracing these various interpretive paradigms, which both underpin the work and ultimately have impacted its creation, the autobiographical turn was taken
to facilitate narrative communication with an audience that would be unfamiliar with particular condition. By necessity, then, my voice is present in the film as subject and storyteller, and needs to be heard within the practice-led research paradigm. However, much consideration has been given to balancing my voice alongside the many other voices heard within the film, to ensure that mine as a solitary voice is not privileged over and above those of my family members and those other community members featured in the film.

Embracing these frameworks has also facilitated my voyage of self-discovery, wherein I have been confronted continually with my own fears, shortcomings and ignorance, and have at times been surprised by what I have discovered about myself, and who I wish to be. I have grown during the course of the film from a position of feeling overwhelmed by the complexity with which Allycia’s condition presented me, to a position of enjoying a new way (still very much a work in progress) of viewing my life as one that will flourish in the company of my family and the various communities that my life now includes. As a filmmaker, these processes have enhanced my understanding of the richness of the medium as a mechanism for communication, both as subject and audience.
In Allycia’s lifetime, a mere fifteen years at the time of completing this work, much has changed in our world. From my perspective, this has occurred nowhere quite as rapidly, or with such potentially wonderful (or perhaps not) ramifications, than in the world of disability. The very word ‘disability’, with its multiple meanings and connotations has been contested, as the medical model’s historical categorisation of persons of physical and intellectual difference has been challenged strongly with the emergence of a social model within academic discourse. This chapter casts a broad net across the vast fields of disability, representation, narrative and autobiography theory. Disability has a complex status: on the one hand, it references lived experience and its alignment with the bodily ‘real’; while on the other, it is used in much popular and high popular culture as a metaphor-generator, a ready source for quick stereotyping. Indeed, as Garland-Thomson (2004) states in her challenge to integrate disability with feminist theory:

Disability – like gender – is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment (2004: 76)
This chapter provides a framework within disability studies that has shaped and informed the creation of the autobiographical documentary film, *18q*: A Different Kind of Normal. Only when viewed within this context can my motivation for making the film be understood fully. The film provides a number of counter-narratives to those narratives examined and explored in academic analysis of the historical portrayal and subsequent treatment of persons labelled ‘disabled’. For those readers and viewers unfamiliar with this terrain, it is necessary to lay some basic foundations to ground the work and its intent, which is to bring forth views about disability from both those persons affected by conditions situated on the 18th chromosome and those who care for them, in a bid to challenge current, prevailing Western disability discourses of tragedy, failure, lack, loss and hopelessness. The contribution the film aims to make is to introduce ‘not just a different interpretation but a different narrative of how they (we) fit into history’ (Kudlick, 2003: 773).

While disability *per se* has been represented in the West throughout the ages and across the arts, and has indeed been a subject of fascination for those in the medical field (Snyder and Mitchell, 2001), there has been a recurrent alignment of disability with loss, tragedy and the need to restore or repair what has been perceived as a state of being that is ‘less than’. In short, the narratives – whether they be literary, displayed on canvas or celluloid, in stone or on the pages of medical journals – vary little in their discourse of placing those whose appearance or behaviour defies an imagined or ‘real’ average or
mean established by a particular culture at a particular time in history as ‘other’.

Representation and narrative theory are explored within the disability context in a bid to discuss the difficulties encountered in telling my own story and the stories of others whose place and authority may be compromised by familial relationships or differing intellectual capacities.

As a mode for telling stories, autobiography is hardly a new phenomenon – although it may be asserted that, historically, this mode of communication was largely available only to those who possessed sufficient means, education and access to modes of distribution available within their lifetimes. The autobiographies of those whose lives were affected by symptoms or conditions consistent with disability – most especially those with intellectual impairment, whose means of communication were limited – will forever remain untold. While at the time of making this film I may not necessarily have been classified as disabled, much of the film is devoted to giving voice to a number of people living with disability and their carers, and so may more appropriately be termed as auto/biographical, with the autobiographical used as a device to bring those other biographies to the screen. However, my desire – and I believe the willingness of those whose stories are told within the film – may be seen to reflect Couser's notion that:

Disability autobiography should be seen, then, not as spontaneous ‘self-expression’ but as a response – indeed a retort – to the traditional misrepresentation of disability in Western culture. (2009: 7)
There is a wealth of evidence indicating that people of genetic difference who experience life with the ‘disabled’ label are under-valued by Western society, when framed within its long and oppressive history (Snyder and Mitchell, 2001; Barnes and Mercer, 2003; Oliver, 1990; Corker and Shakespeare, 2002). There is also a growing body of evidence – which I assert at the risk of sounding melodramatic – that their very existence in the not too distant future is under threat. This evidence exists not in the minds of emotional parents, religious devotees or radical activists, but rather in the growing body of facts and figures populating medical journals, indicating the considerable impact that pre-natal testing is having on the birth rate of people coded with genetic difference (see findings by Caruso et al., 1998; Offerdal et al., 2008; Cheffins et al., 2000). The trends identified in these studies reflect direct correlations between the uptake of new predictive technologies, identification of genetic difference and termination rates. This trend towards the elimination of genetic difference reflects much about the devaluing of people with disability attested to in disability studies.

It is my contention, bolstered by my own and other parents’ experiences with their children born with Chromosome 18 abnormalities, that the medical narrative – a narrative delivered by genetic counsellors and the medical fraternity – increasingly framed within the language of risk and cost, is devoid of hope and tainted with outdated perceptions of what living with disability can be, based on a history of Western oppression and institutionalisation associated with people with disability. This film stands in defiance of the
perceived lack of potentiality of persons born with genetic difference, and
testifies to the value of their lives, and to those around them and the level of
groupment they experience in their lives. In the absence of this evidence,
medical categorisation and genetic diagnosis furnish only a partial, and much-
flawed, picture of what life can be for those living with genetic difference. It is
my opinion that only by the systematic recording and distribution of life
narratives of those born with genetic difference in today’s society can a ‘fuller’
picture be presented to expectant parents. In the absence of these life stories,
a decision based purely on genetic analysis is at best lacking, and at worst
highly negligent.

**Disability Studies**

> Any real change implies the breakup of the world as
> one has always known it, the loss of all that gave one
> an identity, the end of safety.

> -James Baldwin

The emergence of the social model of disability, and subsequent academic
critiquing of the historical construction of disability, have succeeded in shifting
emphasis from the traditional medical model assigning an individual's physical
impairment as deviant to the disabling structures and attitudes of society as
being the greater disabling factors in the lives of persons categorised as
disabled. The figures on the following pages, taken from Samaha’s (2007)
paper ‘What Good is the Social Model of Disability?’, demonstrate, in their
most basic form, the social and medical models of disability.
A Medical Model of Disability

- individual’s physical or mental trait, (for example, a gene associated with deafness)

- individual’s function impairment (for example, inability to hear)

- individual’s disadvantage (for example economic, social, political status)

*Source: Samaha (2007: 1256).*

**Figure 3.1: Reproduction of Samaha's Medical Model of Disability**
The emergence of disability studies, spurred in part by the disability activist movements in the United Kingdom and the United States, has occurred alongside significant medical advances in the realm of both pre-natal diagnosis and the treatments and procedures now available for those born with significant health and intellectual challenges. Such advances in treatment have brought the promise of enhanced health outcomes for those born with genetic
differences and conditions, while emergent pre-natal diagnosis procedures bring a wealth of knowledge to would-be parents, enabling them to make decisions regarding the continuation, or not, of their pregnancies based on the genetic make up of their unborn foetuses.

The political and legal landscapes surrounding the treatment of people categorised as disabled, including the medical and pre-natal diagnostic terrains, have grown in complexity as we see cases for wrongful birth and wrongful life, as well as various medical procedures involving sterilisation and the cessation of life with regard to persons categorised as disabled, populate news stories and broadcasts. Here we see questions of law and ethics come under fire as we, as a society, collectively seek to come to terms with what it means to be disabled, and begin to sift through what it means to invoke human rights and whose rights should or should not be privileged.

Socially, those of our children born with disability are now able to step into schools where once they were excluded. Our adults too, it would seem, have become more visible as the shadow of institutionalised living loses its potency within the life stories of people living with disability. However, stigma and stereotype continue to be coupled with persons whose bodies and intellects sit outside the normal range, and the birth rates of those categorised as ‘abnormal’ at the point of pre-natal diagnosis are on the decline.

It is within this time of great change that my daughter Allycia was born, and as I survey the world around me I realise that she and those like her are pioneers in
a world where the collective known as the disability community has begun to demand to be heard. It is also within this time that my own sensibilities, ideas, values and beliefs have been shaped by my experiences with people born outside what we have come to know as able-bodied or normal.

The drive to bring this work to fruition thus goes beyond a single person, or a single group’s desire to be seen or heard. The need to contribute to the collective voices of the disability community is in many respects an urgent one, due in no small measure to medical advances and the many possible consequences that come with the ability to predict a foetus’s so-called viability. From a personal perspective, I am increasingly concerned about the world awaiting Allycia as she steps out as a woman, and I wonder how welcoming that world will be when evidence suggests that people with disability are increasingly viewed as ‘undesirables’.

The collective voices preceding ours have succeeded in bringing about change in legislation, policy and access to education, and continue to address issues of equity and opportunity to the extent that since the 1970s various inclusions have become part of the United Nations Human Rights tenet, including the incorporation of the disabled population, who are described as:

any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities (UN, 1975: n.p.)
This broad categorisation alludes to the multi-dimensional nature of disability further expounded by the World Health Organization’s framework for measuring health and disability – the International Classification of Functioning, Disability and Health (ICF) (WHO, 2009). This framework not only takes into account the medicalised or biological nature of disability, but has broadened the scope and measurability of disability by including contextual or environmental considerations. The inclusion of other factors, outside an individual’s immediate physical state of being, is indicative of the shift that has occurred in Western society’s disability discourse since the 1970s. This shift can largely be attributed to academic engagement in challenging traditional medical models of disability, with the introduction and formulation of the social model of disability as well as the growing body of work in theorising disability and the emergence of formalised disability studies (e.g. see Oliver, 1990; Barnes, 1992; Shakespeare, 1996).

In recent years, too, there has been an increase in the problematising of normalcy and ableness by theorists who include Campbell (2008), Goggin (2002) and Snyder and Mitchell (2001). I too have begun to wonder what the category of *normal* actually means, and how that equates with *value*. My aim is for the film to raise these questions in the minds of its audience. Moates (2005), who raises the issue of the category of ‘normal’ when discussing the benefits and burdens of pre-natal screening, indicates that the medical fraternity also grapples with balancing new technologies and capabilities
against associated value judgements and ethical considerations concerning
genetic difference:

The role of antenatal screening can be confounding rather than comforting for
many confused by what they believe is routine care. The limits of what is
considered normal keeps narrowing. What is considered a minor variance or a
major anomaly seems to be emerging. And society seems less tolerant of any
differences. (2005: 9)

Price and Shildrick (2002) also challenge the notion of the able body, positing
that ‘the instability of the disabled body is but an extreme instance of the
instability of all bodies’ (2002: 72).

These concerns were not my primary focus, as I did not pursue pre-natal
diagnosis with my pregnancies; however, pre-natal testing is addressed in the
film within the context of genetic difference. My interest in the field has been
spurned by the research conducted for this exegesis, revealing the trends and
the manner in which the results are presented to prospective parents as well
as to those parents seeking analysis after the birth of their children. The
absence of alternative narratives and experiences – and, indeed, the lack of
exposure to persons of difference – offered by the professionals delivering
prognoses to parents has concerned me deeply. The advice I was given upon
Allycia’s diagnosis was quite simply to ensure that she enjoyed the best
possible quality of life. Positive advice perhaps? But instructive, educative or
supportive? I think not.
This diminished value of those categorised as disabled persists in the medical discourse. In particular, texts relating to pre-natal testing for birth defects reflect underlying value judgements in the use of the words ‘benefit’ and ‘termination’ in the same sentence when delivering conclusions derived from statistical data concerning increased termination rates as a consequence of improved pre-natal identification of genetic difference. For example:

The rising termination rate in younger women suggests that the benefits of antenatal screening are now extending to the lower risk younger age groups.

(Iliyasu et al., 2002, n.p.)

While the use of pre-natal technologies and subsequent delivery of prognoses are important issues to be addressed by us as a society, and are dealt with in the film, this is not its central focus. Allycia’s life does reflect some of the tendencies and symptoms outlined in the medical literature, so the fact that she experiences life a little differently because of her physical and intellectual challenges is not at issue. Within the film and this thesis, then, Allycia’s physical and intellectual status per se are not contested – she has had to undergo medical procedures and therapies, takes medication daily and attends a special education class for her ongoing education. It is these everyday ‘ways of being in the world’ that constitute her differing experience of life when I compare the childhood experienced by her average, normal siblings. These actions and interactions are what have been required to sustain her health, well-being and growth. What is at issue is how ideas about her status, her
capabilities and her potentiality to engage in and enjoy her life, with all its ups and downs, are subject to value judgements by the society in which we live. While the experience of living with a Chromosome 18 deletion is rare, many facets of our lives intersect with the lived experience of others living with congenital disability in today’s Western society, and have enabled us to identify at a number of levels with a global disability community that, while diverse and heterogeneous in nature, can be seen as sharing similarities in terms of the challenges we meet. However, there are significant differences between experiencing life with a congenital disability and facing life with a disability that is acquired later in life, either through illness or accident. These differences – which may be described in terms of Riessmann’s ‘disruptive life events’ (2001: 696), which she mentions in her discussion of biography and narrative – affect both the person with disability and their carers in markedly different ways.

The distinction between congenital and acquired disability is critical to understanding the intent of the film 18q-: A Different Kind of Normal and the ensuing exploration of the notion of loss associated with the many representations of, and narratives about, disability that have become synonymous with the disabled experience in a Western able-centric society (Watermeyer, 2009). This notion of loss has been perpetuated over time with the use of disability as metaphor for loss (amongst other negative stereotypical imagery in Western literary and filmic traditions (Mitchell and Snyder, 2000; Longmore, 1987). These traditions continue and have become part of modern day discourse, permeating news reportage and current affairs programming as
well as fictional and documentary film (Oliver, 1990; Barnes, 1992; Longmore, 1987; Norden, 1994; Mitchell and Snyder, 2001; Darke, 1999).

For rare conditions, newsprint, broadcast media, cinema and the internet are the major sources of information for the general population, given that the likelihood of meeting persons living with these rare conditions is unlikely. Hence the public’s way of knowing persons of difference – albeit distorted by whichever lens, gaze or ideology is framing an individual’s acquisition of knowledge – will primarily be via the aforementioned media. With the continued stereotypical portrayals of persons with disability as tragic, in need of repair or as the ‘feared other’ in the media, the quality of life that might be expected by individuals living with disabilities is rarely reflected accurately. (Darke, 1999; Corker and Shakespeare, 2002; Mitchell and Snyder, 2000; Snyder and Mitchell, 2001). Ross (1998), in her discussion of a BBC study exploring disability in mainstream broadcast environments undertaken in 1996, asserts that:

The lack of contact that programme makers have with ‘real’ disabled people and their fear of disability more generally, encourages an easy slide into rearticulating and perpetuating normative, orthodox and familiar renditions of disability. (1998: n.p.)

This diminished positioning of people living with disability is evident in many quarters of society, including those charged with directly affecting their status.
despite a drive towards political correctness in addressing this minority. For example, the vision statement on Disability Services Queensland’s website (2009) reflects the project of disability in its simplicity – and indeed my film is an endeavour to contribute to this vision:

Our vision is a society that values people with a disability, people with a mental illness and people who are ageing.

This statement reflects the experience that we in the disability community know to be true – people sitting ‘outside’ normal or average do not enjoy a position that is seen as valuable. That a government department’s vision statement should reflect a need to elevate the status of its citizens to one of value speaks volumes.

The lived experience of people with disability in modern Western society varies greatly in spite of the blanket categorisations and descriptions used to bundle them together for political and economic expediency (University of Leeds Centre for Disability Studies, 2002). Those people collectively labelled ‘disabled’ have only in recent times become visible, active participants in wider society, following the systematic dismantling of government-funded institutions. With improved medical outcomes and growing support in the welfare system enabling parents to care for their children with disabilities at home, the potentiality for people previously thought to be uneducable and unable to participate and engage in wider society has expanded. The last thirty years have seen people with disability acquire previously unavailable educational
opportunities, engage in higher education and the arts, marry and have families.

This progress, when viewed historically, is revolutionary; however, it garners little attention from mainstream media, save for those times when an individual or group is identified within the standardised newsworthy stereotypes that persist in the construction of the disabled: the super-crip as overcoming great adversity; the heroic carer; or the tragic and fallen other.

Increasingly, there is debate within disability scholarship concerning the social model, articulations of impairment versus disablement, the inclusion of a critical realism approach and how to continue to move the ‘place’ of people with disability forward in a society increasingly intent on perfecting the body to a culturally agreed desirable form and ‘norm’. The drive towards a successful life, regarded as synonymous with the acquisition of a professional job title and appropriate material gain, further marginalises those whose bodies and minds resist restraint and do not conform to traditional workplaces. As well as these barriers, laws concerning disability and the appropriation of medical procedures and legislature remain in a state of flux, as key decision-makers grapple with how decisions should be made and by whom, as well as how the social model can be of use in policy-making (Samaha, 2007). Key to these issues are the ways in which people with disability are presented and represented, and in many cases how their lives may be re-imagined at this critical moment in history.
Representation

_I may be the star, but you are the heavens._

- **Dustin Hoffman**
  (dedicating his Oscar to Kim Peek, the 'real' Rain Main)

As outlined in the previous section, how people with disability have been represented historically in the West has increasingly come to be seen as problematic in terms of the portrayal the quality of lives they may lead and how they might contribute to and be part of 'normal' society. Whether these portrayals exist in the fictional or non-fictional realms, the message has shown little variation from the stereotypical imagery we have come to associate with what we now call 'abnormality'. The question of appropriate and/or adequate representation of the 'disabled community' is one that continues to raise considerable debate in modern Western societies. In her review of research about media and disability, Barbara Kolucki cites remarks made by Micheline Mason, a disabled parent and writer, while addressing media people who encapsulate the current state of affairs:

>You are as shut out of our world as we are shut out of yours. We do not see the image of our real selves anywhere, and we are aware that we are not considered to be part of the audience. (Kolucki, 2001: 18)

According to Barnes (1992), stereotypical representations of people with disabilities in the media include:

- the pitiable and pathetic
• the object of violence
• sinister and evil
• atmosphere or curio
• super cripple
• object of ridicule
• their own worst enemy and only enemy
• burden
• sexually abnormal
• incapable of participating fully in community life
• as normal.

Longmore (1987), Darke (1999), Norden (1994) and Mitchell and Snyder (2000) further the discussion of these categories and their proliferation in fictional accounts of disability, ranging from fairytales and children’s books to cinematic film.

The manner in which Norden has constructed his critique of disability and cinematic convention is pertinent to this project because he has laid bare the way in which historical events, socio-political climates and cultural change have, over time, influenced the portrayal of disability in fictional cinema. What his work reveals in many respects reflects the project of the social model of disability – notions and evaluations of difference are cultural constructs that, over time, are subject to flux and change, depending on myriad factors.
Ellis (2004) situates the stereotypes that figured large in our particular cultural context and places Norden’s (1994) work together with Barnes’ (1992, 1997) writings as part of her critique of the ‘place’ and function of disability in cinema in that period. Her research lends significant weight to the way in which disability representation has been constructed in fictional works, and how over time imagery reflects changing attitudes and engagement with what we have to come to know as disability. Her later critiques (2010) of more recent films, including *The Black Balloon* (Down, 2008) and Adam Elliot’s *Mary and Max* (2009), are further evidence of the state of flux to which disability representation is subject in fictional film and, interestingly, the engagement of writers and directors in the field.

Simply and succinctly, people with disability have endured and survived a history of degraded, voyeuristic, sensationalised representation. Rather than being presented as persons with unique identities, it is their difference – or their ‘lack’, in referential terms – to the average human being that has been displayed over time and has succeeded in othering them from the rest of society. This othering of those of differing physical and/or intellectual impairment can then be seen as the forerunner of the construction of a group now collectively called disabled. Academic interrogation of this categorisation has embarked upon the deconstruction of this group in a similar fashion to the feminist, gay and racial theoretical endeavours, resulting in the challenging of able-bodiedness.
The call for changes in representation extends beyond the broad category of disability studies and are not confined to countries outside our own, although the volume of work devoted to disability studies in Australia pales in contrast to the two leaders in the field, the United Kingdom and United States. However, apart from Australian key theorists engaging in disability discourse, including Goggin and Newell (2005) and Campbell (2008), academics from other disciplines have taken up the challenge of confronting stereotypical portrayals in our media. The reliance on much-used stereotypical images and storytelling techniques pervades our Australian media, as is evidenced in studies including Symonds’ (2006) exploration of Channel 9’s *A Current Affair*. Symonds, from a special education background, identifies the continuation of narratives outlined by Barnes (1992), which are used repeatedly in the programmer’s approach to disability, alerting the reader to the lack of depth and complexity given to disability issues and the absence of an educative voice in reporting disability.

While much has been written and agreed upon in terms of what constitutes a negative portrayal of persons living with disability, the project of representing the ‘disabled other’ in what might be seen as a positive light is not so clear, and is examined in some length by Darke (1999), Hevey (1992) and Mitchell and Snyder (2000). The disability community is one that has been ‘bundled’ together, and it encompasses people from all walks of life. It is improbable that a definitive positive image-making project could be produced; however, I believe chapters highlighting the various groups, cultures and individuals, and how they carve out lives for themselves amidst the everyday struggles they face, goes some way towards creating an archive of sorts that may serve as a
reference point for people who wish to know more about disability, those who face living with disability and those in our communities charged with their care, including medicos, educators and law-makers. For Snyder and Mitchell:

The acceptable image legislated by the social realist would be based first and foremost upon a representational advocacy wherein images function as a weapon of political action and as a redress to social incomprehension. (2000, 24)

The difficulty in defining the way in which an image is viewed and perceived by the diverse members in the disability community demonstrates the ‘volatility of the interaction between audience reception and media imagery in the social construction of disability’ (Symonds, 2006: 4). This became crystal clear at a very personal level when comparing my reactions to films such as *The Elephant Man* (1980) and *Forrest Gump* (1994). My emotional reaction of compassion and despair, recalled from viewing *The Elephant Man* at the age of 15 does not find any resonance with Darke’s scathing review that it ‘is not the liberal, tolerant and pro-difference film’ (1999: 341) it was touted as being, but rather akin to a voyeuristic sideshow.

So too, my reading of *Forrest Gump* as inspirational and as having been the impetus to re-imagine what a life with disability might be like in the year Allycia was born, would appear to be naïve, utopian and uninformed when compared to the criticisms of the film made by academics such as Karen Boyle (2001), who decries the portrayals of both Forrest Gump and Lt Dan Taylor. To be very honest, I was not watching the film with a need to review film narrative or
technique, nor was I viewing it from a vantage point of challenging the United States versus Vietnam War debate. I was a parent seeking some hope about how I would create a meaningful life for my daughter in the absence of stories that might have enlightened me a little more.

Reflecting upon my gaze at that time, and how I viewed these films (Forrest Gump remains a family favourite in our house – my son christened the first car he bought ‘Jenny’), I had no idea of the life that lay before us. I had yet to grapple with issues of ongoing medical and specialist treatments or the minefield that is education for special needs children, and I had not even begun to question my own reactions, beliefs or values around disability – I viewed the film through a particular lens that had limited experience with living with disability, and no real education in reading media imagery. I had never even heard of the phrase ‘social construction of disability’.

With this new-found knowledge, and upon beginning this project, I have become keenly aware of the different audiences who might view the project as well as how those of us featured in the film would view ourselves. How would I represent our lives truthfully without ostracising an audience who in all likelihood would be as culturally illiterate as I was before Allycia arrived in our lives? Just as the disability community – and indeed the Chromosome 18 community – is diverse, so too the possible ways to structure a film and tell a story are almost limitless.
Within regard to representation in the context of making this particular film, I was aware constantly of my desire to inform an audience and to ensure that this was not just an exercise in working out my own ‘stuff’ – or, as some have asserted in the discussion of autobiography, navel gazing. My desire is for our community to be seen and heard; however, I have become resigned to the fact that members of an audience will see the work through their own particular lens.

These lenses are tainted by not only the historical inculcation of what it means to be disabled in Western society, but also by the gaze and the construction of the normative as discussed by Garland-Thomson (1997). She asserts that the normative is ‘powerfully etched into collective cultural consciousness’, wherein she lays bare ‘culturally generated and perpetuated standards [such] as "beauty", "independence", "fitness", "competence" and "normalcy” that have succeeded in excluding and disabling some human bodies while ‘validating and affirming others’ (1997: 7).

These standards are challenged by the act of making the film, and this challenge is entwined in the narrative of the film, most specifically when notions of beauty are addressed by Rick Guidotti of the Positive Exposure Project (2008) and when the concepts of competency and normalcy are discussed by Irene and Scott Lammers, the parents of three children, two of whom are affected by Chromosome 18 differences. Rick, an accomplished New York fashion photographer, asserts that we are ‘just trained not to see it’ when he speaks of the beauty he has found since beginning to photograph
people living with genetic difference. Irene and Scott speak frankly about their own preconceived ideas about intellectual impairment, and the changing expectations that have accompanied their journey with their family.

I am keenly aware that bringing forward the ideas and the issues the film attempts to showcase is a little like shovelling snow in the midst of an avalanche when placed against research indicating an increased drive towards ensuring the normative is fashioned in utero (Rothman, 1986; Hawthorne, 2006) and the changing attitudes about motherhood that have emerged since the introduction of pre-natal testing. The work of these researchers indicates increased anxiety about the normalcy of unborn foetuses and that the choice to continue with pregnancies destined to deliver genetically deviant children is irresponsible. However, capturing Garland-Thomson’s notion of contributing ‘to recasting disability as an occasion for exuberant flourishing’ (2007: 114) became my mantra. It was important for me not only to recast of our children and adults affected by Chromosome 18, but also show that our changed role as parents had become an opportunity for us to flourish.

In many respects, this work may be categorised as sitting within the field of ethnography, specifically a postmodern ethnography wherein the work is:

is a cooperatively evolved text consisting of fragments of discourse intended to evoke in the minds of both reader and writer an emergent fantasy of a possible world of commonsense reality, and thus to provoke an aesthetic integration that will have a therapeutic effect (Tyler, 1986: 125).
Specifically, I have endeavoured to emulate Tyler’s (1986) project of making
the familiar unfamiliar, and then familiar again. Using Tyler’s perspective, I
have adopted the attitude that the purpose of my work is somehow to evoke an
alignment of our experiences with those of an audience – in essence, I am
working towards closing the gap, not by negating or hiding our differences but
by aligning those differences with experiences that may be seen as more
universal.

I adopted the autobiographical approach after a year of working on the project
as a consequence of noticing that the work at the time was still feeling
somewhat ‘distant’ from an audience unfamiliar with disability. I was
determined to create a piece that would take an audience with me from
unknowing to more knowing, showing my flaws and shortcomings along the
way. However, in much the same way that Tyler (1986) admits that a
postmodern ethnography may ‘never be completely realized’ and that:

> Every attempt will always be incomplete, insufficient, lacking in some way, but
> this is not a defect since it is the means that enables transcendence.
> Transcendence comes from imperfection not from perfection. (1986: 136)

I have surrendered to the fact that my work will not achieve perfection, but that
despite this it may spark some discussion of what might constitute perfection
and imperfection and how we have come to understand those categories. I
also realise that the representation of our lives on screen cannot equate with
engaging with us ‘in the flesh’, or truly impart the impact of our experiences – a
viewer will not truly ‘meet’ we ‘others’, but at least they will know we are here and that we have taken the opportunity to tell some of our story.

**Narrative**

*Stories are the most effective ways of changing minds.*

- Howard Gardner

Garland-Thomson (1997) describes the narrative of corporeal difference as having succeeded in not only excluding, but as implicit in, the erasure of counter-narratives. This applies specifically to those whose intellectual capacities are deemed diminished, and most particularly those who do not have sufficient command of verbal or written communication. The accounts we have of those lives lived exist only from the perspective of those who viewed and studied them. If one’s sense of self is achieved via narrative, or by the stories we tell each other about one another, as King (1997) posits, how does one achieve a sense of self without a referent narrative? Narrative – or, from Schegloff’s (1997) perspective, the act of telling stories – enables people to ‘do something – to complain, to boast, to inform, to alert, to tease, to explain, or excuse, or justify’ (1997: 97). Until recently, then, those living with intellectual impairment lacked the means to tell their story.

As I moved through the process of creating this work, the idea of storytelling – how stories impact upon us, whose stories are privileged and whose stories we relate to – has become of great interest; most especially, whose stories gain
supremacy when speaking of congenital disability, particularly within the intellectual impairment domain.

At the time of Allycia’s birth, there were narratives available to me in terms of disability – the tragic, the oppressed, the impoverished, the diminished; however, none of these was a story I wanted to tell myself, and I wasn’t particularly keen on what they said about who Allycia was or might become. The drive to commit this narrative to paper and to a documentary film thus was born of a void, a vacuum at the time of Allycia’s birth. That void has since begun to be filled – multiple snapshots of narrative exist on the website now devoted to Chromosome 18, with the website itself being a compilation of the medical narrative associated with being born with this condition. The lived narratives of families affected by the condition are now increasingly visible. 18q-: A Different Kind of Normal is the first extensive completed work to explore the condition, and to communicate some of the experiences of our family, other families and individuals living with the condition. So the story of our lives has begun to be told: the stories of the bodies of persons categorised as disabled alongside the stories of how those persons have become accustomed to living in a society that collectively views them as wanting, in need of repair, lacking.

In aspiring to reflect Garland-Thomson’s (2007) notion insisting that ‘shape structures story’, the narrative works to recast disability ‘as an occasion for exuberant flourishing’ (2007: 114). Recasting in this context needs clarification, as the vital distinction between congenital and acquired disability with regard to
the stories we tell ourselves about ourselves must be maintained. For within the narratives we see in films such as *Murderball* (2005) lies the experience of loss – the loss of a particular way of living. For persons who once walked unaided, and who need to refigure their lives from the vantage point of a wheelchair, loss is undeniable. The difference between the narratives explored in this film and those brought to the screen in *My Flesh and Blood* (2003), for example, demonstrate how exuberant flourishing may emerge. Loss is explored in both films; however, many of the family members in *My Flesh and Blood* enjoy and engage in life alongside the difficult and often painful experiences associated with their various conditions – conditions with which many of them were born. Within the narrative of congenital disability in my film, the loss and refiguring of life are experienced by the parents, including myself – a loss of unrealised expectations of how we imagined life would be after the birth of our children. There are some references to loss experienced by persons affected with the condition; however, for the most part, the film is directed towards demonstrating the fullness of the lives of those born with this genetic difference.

Placed historically, this exegesis and film work towards recovering what Atkinson and Walmsley (1999: 204) refer to in their ‘discussion of the potential of autobiography as a means to change the power relationships in disability research’ (1999: 203) as ‘lost voices’ (1999: 204). Indeed, in the film Susan Baldwin Shafer asserts her place within her community ‘to speak for those who cannot speak’. This film aims to give voice to the Chromosome 18 community – to begin to provide a living history of the meaningfulness of our lives.
At this point in time, medical stories about genetic deviance continue to reign supreme, for the most part remaining unchallenged. This is perhaps due in part to Smith and Sparkes’ (2008) assertion that:

People are born into a culture that has a ready stock of narratives from which they draw upon, appropriate, adapt, apply and perform in their everyday social interaction page. (2008: 18)

I am concerned about how the ‘ready stock’ of medical narratives of deviance intersect with the emergent stories of those living with that deviance, and how and on what or whose authority these stories are being communicated to prospective parents receiving pre-natal diagnoses. In essence, whose lens is being privileged during this exchange of information, and on what basis – outside medical narratives – are critical decisions regarding continuation or termination of pregnancies being made? Certainly the medical statistics currently being collated indicate that there has been a marked decline in birth rates relating to genetic deviance since the uptake of pre-natal diagnostic technologies. This tendency continues in spite of the emergence of a growing body of work that challenges the notion of able-bodiedness (Goggin, 2002; Campbell, 2008) and an increased presence and awareness of the ‘disabled other’ in our schools and workplaces.

A genetic counsellor’s story is imbued, directed and gleaned from the medical stories to which they are subject during the course of their studies. They are
embedded in the very story – the medical story – that has been contested by
disability scholars over the course of the past 40 years. A genetic counsellor
must possess an above-average intellect in order to engage with the material
and then communicate that information to those being counselled. By
extrapolation, then, we may say that the genetic counsellor’s lived experience
is somewhat removed from that of a person born with intellectual impairment.

Klotz (2003) outlines some of the historical shortcomings in the study of
disability, and examines the failure to validate the lived experience of people
with intellectual disability, which in some respects may underpin the difficulties
in representing and incorporating those ‘othered’ narratives into the
mainstream media:

Rarely do any of these more recent accounts seek in any way to enter into the
lived realities of people with intellectual disabilities as persons whose lives are
much more, or other, than the products of these supposedly overarching and
deterministic constructs. We tend to learn more about what they signify and
represent as objects of sociocultural constructions rather than who they
actually are, as human subjects creating meaning and engaging in
relationships with others (2003: 13).

She reiterates that the voices of those impaired remain unheard, and that
access to those ‘othered’ experiences continues to be elusive. As a result of
these processes, she restates Whyte’s view that:
we tend to remain outsiders, unable to fully grasp or engage with the lived realities of such people negotiating with the cultural values and beliefs that surround them (Whyte, 1995: 240–1).

By positioning myself as autobiographer and biographer, I offer viewers the opportunity to see themselves and the 'othered' via my own narrative – that of the mother – which occupies both positions of insider and outsider simultaneously. In the absence of narrative about lived experience, the perceived potentiality of a person born with a chromosome condition can at best be an educated guess in terms of that person’s physical or ontological state – the basis of medical diagnosis. However, until there is the presentation of the many versions life can take from an epistemological standpoint, the story – the narrative – remains incomplete. Certainly there is a significant body of evidence that supports some genetic deviance as being unsustainable, but given that people such as Susan Baldwin Shafer, an adult affected by Chromosome 18 difference featured in the film, was not diagnosed with Chromosome 18 until she was 27, it must be accepted that there is significant variation amongst individuals born with this condition, in much the same vein as persons born with other chromosomal variations such as Down Syndrome.

Within these Western medical discourses of variation and deviance, the notion of ‘otherness’ is enshrined within the infallibility of scientific inquiry which, when coupled with the notion of ‘risk’, succeeds in portraying and communicating the undesirability of ‘otherness’. This discourse remains stuck within the confines of the normal versus abnormal binary, based purely on the formation or mal
formation of the genes – an ongoing scientific mystery that continues to intrigue medical researchers and delivers as many questions as it answers.

It is this construction of ‘otherness’ within these narratives that 18q-: A Different Kind of Normal wishes to challenge, endeavouring to embody what Chris Sarra, in his interpretation of Bhaskar’s (1993) ‘core universal humanity’ with regard to Aboriginal identity, has substituted as ‘the notion of a common core of otherness, as constituting the essence of human being’ (Sarra, n.d.) Further, Sarra argues that ‘we should regard the same as a tiny ripple on the sea of otherness’. He believes that this perspective enables ‘the right to be other’ and ‘captures something of the wonder and strangeness of being’ associated with Aboriginal spirituality. I too have been captured by the wonder and the sometimes strangeness of being that Allycia and her peers have brought to my life experience. I have also become increasingly aware of how my own embedded versions of normalcy and strangeness have been challenged, and continue to be.

In fashioning the film, I have been aware of maintaining a level of accessibility to audiences who are not intimately familiar with disability and have worked against the ‘spectacle’ of disability that has been used as a key driver in disability narrative, both in fiction and non-fictional film. The ‘spectacle’ I was seeking lies more in showing how affected adults see themselves and others, and how parents of people born with disability have sought to rewrite, and re-imagine different lives to those they once believed lay ahead for them. I have included stories that reflect the ‘sameness’ and ‘difference’, with those affected
by the condition telling their own stories. In presenting these stories, some of Davies and Jenkins' (1997) assertions about people with disability and the way they see themselves are demonstrated. Some of their life choices are restricted, and there is a dependence upon others for some of their needs. However, the young adults featured in this film do demonstrate an awareness of their biologically determined difference, as well as of normalcy.

Kathryn and Martin’s story of how they met and fell in love is a high point of the film for me – by their own admission, ‘it was love at first sight’ and ‘they love just like normal people do’. Lucinda states she ‘doesn’t like that word’ when her mother utters ‘abnormality’ in reference to her condition. Elizabeth wants a family just like hers – one child born with 18q and one child without; she likes the way her family operates. There is a knowing and an awareness of difference by the young adults during the course of the interviews; however, I never got the sense that they saw themselves as less than others, or in need of reparation or restoration. Certainly they each face challenges, but challenges in life are not the exclusive domain of those living with disability – they are a universal experience.

The work, then, attempts to furnish some answers to Klotz’s (2003) call to go beyond the social model of disability by ‘giving priority to the lived experience and negotiated meaning of “disability”’ and ‘enhance our understanding of disability as a complex social, cultural and biomedical phenomenon’ (2003: 24). Studies using autobiographical approaches explored by Atkinson and Walmsley (1999) demonstrate a shift in focus in recasting disability narrative by
privileging the stories of those living with disability over those researching them. In doing so, they advocate for working towards Zarb’s (1992) ‘emancipatory research’ in shifting the power relations previously employed in what was implicit in ‘participatory research’ (1992: 125).

Sunderland et al.’s (2009) *Missing Discourses* is an example of a more diverse approach to research methodologies, which includes disability policy research and the conducting of life story interviews and focus groups with people living with disability – albeit acquired rather than congenital disability. However, the title is indicative not only of the lack of narrative, but of emerging counter-narratives unfolding as these new approaches are employed. Scholars within special education also have called for more widespread challenges to the continued one-dimensional reportage and stereotypical storytelling seen on programs such as Channel 9’s *A Current Affair* (Symonds, 2006). Symonds posits that these practices succeed in the perpetuation of narratives that support diminished life experiences of those living with disability, rather than offering an alternate reading that ‘empowers the expression of the diversity they individually possess’ (Davis and Watson, 2002, in Symonds, 2006: 159).

Programs like *A Current Affair* in many cases may be one of the few access points the general population has to disability experience, particularly when it comes to rare genetic conditions. In continuing to furnish the ‘same old, same old’, opportunities for countering these representations to the greater community remain limited. As Plummer (1995: 87) states, ‘for communities to
hear, there must be stories which weave together their history, their identity, their politics’.

In weaving its history, identity and politics, then, a community is concerned with itself, and disability increasingly is being seen as sitting squarely at the centre of historical inquiry, both as a subject worth studying in its own right and as one that will provide scholars with a new analytic tool for exploring power itself. McHenry (2007) states further that:

> It is necessary to deconstruct the disabled subject and rethink notions of the Other in order to provoke any real challenge to the discourses of perfection and wholeness that dominate the cultural imaginary. (2007: n.p.)

At this juncture, it is pertinent to return to this film and the shaping of my own narrative and the others included in the work, given that one of the major drives in the work has been to challenge the ‘perfection and wholeness’ that does indeed dominate our collective ‘cultural imaginary’. 

Allycia’s conception, birth, open-heart surgery, diagnosis and subsequent prognosis may be viewed as ‘disruptive life events’ within the context of my life, in that these events and experiences can be seen to ‘fundamentally alter expected biographies’ (Riessman, 2001: 696). I cannot recall what I may have thought ‘my expected biography’ was some sixteen years ago, but I think it is fair to say that it probably did not involve giving birth to a third child with multiple disabilities. I would wager, too, that I certainly would not have had the
capacity to imagine ‘who’ that person born with a rare genetic condition might be, or the impact her arrival would have upon my life.

One of the most significant outcomes for me following this series of disruptions has been the way in which I now view my life as being so intimately infused with the social, economic and political environments within which we exist. One of the many new roles in which I have found myself engaged is that of advocate – which, within the disability context, is inextricably entwined with activism. The very act of making this film may be situated within Snyder and Mitchell’s (2008) notion of the ‘activist context itself as being influenced by disability experience while using the film to encourage solidarity on behalf of bodily limitations’ (2008: 17).

This growth in self-awareness, and the opportunity my study and the making of this film has afforded me to reflect upon the way in which Allycia’s birth has changed me, have brought me to new understandings of how the stories we tell ourselves can influence the way we live our lives. Who our heroes are and how a good life is lived and what constitutes that good life are communicated throughout our society by the stories told and retold by ourselves, about ourselves, to ourselves. Certain stories achieve greater popularity and greater desirability than others, but there are many versions of how a good life might be lived – though a life with disability has rarely been portrayed as a preferred state of being in today’s West. In actuality, within the dominant narratives to which we continue to be subject, it is a state to be avoided at any cost, and
when encountered is still in need of reparation or erasure. Linton (2007) best articulates how I see disability today:

I fear that in the present century, the disability line could wreak more havoc. It could increasingly determine, who based on their outward appearance or functioning and significantly on their genetic makeup gets to do what and under what circumstances. Where and how we live and whom we mate with, where we go to school and how we are incorporated into the life of the community. While this sorting system has been in place for centuries this new science genetics, will lend an air of authority and seeming rationality to these decisions, that will be very hard to fight. (2007: 245)

Contesting these drives by providing counter-narratives about living with disability is one of the major goals in this work, as is bringing enhanced awareness of the diversity that just one genetic condition presents. In this representing of our community, it has been difficult to fashion an over-arching narrative that flows due to that diversity I see in our community and the changing nature of our lives. I have endeavoured to take the viewer back to the beginning of Allycia’s life, and represent my learning – and in many ways my unlearning – along the way via an over-arching narrative that is occupied by multiple micro-narratives woven into an intelligible, logical progression.

Ironically, the very aim of this project is to make the work here – the images, this story of difference – redundant, so that these kind of narratives become more numerous and more accessible to more people. My desire is to contribute to a more ‘knowing’ society in that the work, in rendering the invisible visible, opens up a space for a different kind of normal; that the lives
we present will eventually become unremarkable in terms of the spectacle that
disability invokes.

Autobiography

Every autobiography is concerned with two characters, a
Don Quixote, the Ego, and a Sancho Panza, the Self.
- W.H. Auden

I was inspired to begin this project when, in 2004, I heard an interview with Dr
Jani Klotz on ABC Radio. Her story spoke to me in a way that no other had
until that time. Her personal experiences as one of seven children, three of
whom were intellectually impaired, formed the basis for her academic interest
in anthropology and the direction her life had taken. The following excerpt was
one that captured my attention, and was to prove to be the starting point of my
work:

there’s a tendency in the Christian tradition to think of intellectually disabled
people either as manifestations of Sin, particularly the mother’s sinful
behaviour, or conversely as holy innocents. Neither of which accepts
intellectually disabled people’s differences as fully human, as fully equal.

By focusing so much on this notion of reason and intelligence we have denied
the full range of what the human creative potential is as an intellectual thing, as
a mental thing. So what I’m trying to argue is that this idea of someone being
intellectually disabled is anathema, I mean they are intellectually different. The
way that their mind works is different. So it’s not to deny reason and rationality
are human tools, it’s just to argue for a more inclusive, a broader sense of what
the mind is about. (2004: n.p.)

I had been subject to the Christian viewpoint at both ends of the scale, as well
as the well-worn phrase ‘God only gives special children to special people’ –
one of the many contradictions in our Westernised culture that perplexed me.
Equally, I was aware of Allessia’s ‘different way of being’ in the world when I
compared her with her siblings, but here too Adam and Kristina, her brother
and sister, interacted differently from one another. I did not, however, feel that
any of my children’s ways of being were superior or preferred. Certainly
Allessia’s young life has been chequered with experiences vastly removed from
those of her siblings, due to the different way her body ‘works’, and this has
impacted upon her and our lives. As her family, we too began to broaden our
‘sense of what the mind is about’ as we grew to know Allessia. Many around us,
including the many specialists and service providers with whom we dealt,
found it a little more challenging, to say the least.

This is not to minimise the impact Allessia’s birth was to have on all of our lives.
Her disability has shaped our lifestyle and, as I state during the film in
voiceover, I believed in those first years of her life that my own life was over. It
has been integral in shaping this work for me to reach back and examine
those ideas about what I thought my life was supposed to be. Clearly, it did not
include taking care of a person with disability, and all that I believed and was
told such a role would entail. Upon reflection, that belief was perhaps in part
due to the way in which I viewed what ‘disability’ meant, and my interest in how
I came to hold those views has informed the film.
The only ‘stories’ about Chromosome 18 anomalies available to me were those delivered by the genetic counsellor, and these held little optimism or hope, given the available data at that time. I did not know anyone with this condition, so I began to seek out disability stories in general. Television and film were avenues that were readily accessible, but as discussed earlier in this exegesis, I preferred the fictional accounts to those proffered by mainstream broadcasters. The fictional accounts were great tools when it came to freeing up my imaginings about what life might be like with a disability, but were hardly instructional. Eventually, following a conversation with one of Allycia’s teacher aides, I came across the Community Resource Unit, and I was finally able to meet other people living with disability and their carers. My quest – although I wouldn’t have termed it as such then – was to uncover other people’s stories: in essence, I was looking for biographies and autobiographies, searching for ‘someone who had walked this road before me’ (Wain, 2010).

Given this very brief background, it is not surprising that I felt compelled to begin exploring some of the ideas Jani Klotz had discussed, and to somehow challenge the ideologies that had confounded me. My original intent was to somehow contribute to giving a voice and presence to people born with intellectual impairment, specifically those affected by Chromosome 18 differences. This intent was spurned by the isolation we had experienced and the absence of our collective stories. I had no desire to be in front of a camera, nor did I wish to disclose my private life on screen – in truth, our lives in general are quite unremarkable and I grappled with what could possibly be
interesting to a viewer apart from Allycia’s rare genetic status. When the question of how one films one’s own life from a purely technical aspect is added into the equation, I was extremely hesitant.

Then, in the second year of the project, as I was experiencing difficulties in structuring the film and creating an accessible piece for a condition that is rare and under-reported, my then supervisors, Dr John Hookham and Dr Gary MacLennan, encouraged me to use my personal story of discovery as a vehicle for driving the film. In retrospect, in terms of making the film more accessible to an audience that would for the most part be unfamiliar with this condition, it had seemed that autobiography, as a storytelling device, could serve a number of purposes for the film.

My discomfort before the camera was equally matched by my anxiety about how disability scholars would receive my work, given the increasing level of criticism directed at emergent disability life stories. My research had indicated marked anxiety around the disability ‘autobiography’ as an emancipatory tool for those born with disability, due to the individualising of the stories being told and how, in many instances, rather than subverting traditionally held ideas about disability, disability autobiographies were seemingly falling back into highly contentious stereotypical constructions. For example, Mitchell (2000) argues that:

> Instead of serving as a corrective to impersonal symbolic literary representations, disability life writing tends toward the gratification of a personal story bereft of community with other disabled people. Even the most
renowned disability autobiographers often fall prey to an ethos of rugged
individualism that can further reify the longstanding association of disability
with social isolation. (2000: 312)

Mitchell does acknowledge that his position stands in contrast to those of a
number of other scholars, noting that they see ‘disability writing as a corrective
to the insubstantiality of literary portraits’ (2000: 312). Nevertheless, he is
concerned that the continuation of the single, self-reliant identity cast in first-
person literature lacks ‘the documentation of disability as a communal identity’

Bérubé (2000), on the other hand, offers a different perspective by juxtaposing
the history of slave narrative with the emergence of disability life writing. In
citing an example of disability life writing featured in the work Count Us In:
Growing up with Down Syndrome (2000), he draws a poignant comparison
between the two fields. Just as the slaves were believed incapable of ‘reason,
could not write, could not narrate their life stories’, so too an ‘entire population’
of people born with Down Syndrome was also thought to be incapable of
communicating in meaningful ways in the years preceding their emancipation
from institutionalised living and diminished access to education (2000: 338–
43). Smith and Sparkes (2008) likewise support Bérubé’s position:

[N]arrative inquiry bears within it the promise of fashioning a kind of
scholarship that seeks to practice a deep fidelity to the possibilities of societal
and individual transformation, resistance and living life differently. (2008: 19)
They offer examples of counter-narratives, including Swain and French’s (2000) affirmative models of disability, Frank’s (1995) quest narrative and Richardson’s (1990) collective stories (1990) that they believe challenge the historical representation of disability and ongoing ‘social oppression’ positing that ‘if we change the stories we live by, we quite possibly transform and change our lives and society too’ (Smith and Sparkes, 2008: 19).

What appears to be key to these discussions is a matter of agency; however, a way through this dilemma may be the embracing of Archer’s (1995) view that we:

need to distinguish between collective agents and individual actors. The reality experienced by the collectivity is not reducible to the personal reactions of its members; nor is the subjectivity of the latter understandable without reference to the objectivity of the former. (1995: 120)

Stastny (1998), with his background in psychiatry, film and academic practice, extends the complexity of how best to proceed in representing these counter-narratives with his discussion of the challenges he confronted in his endeavours to bring the experiences of those living with psychiatric disability issues to the screen. He raises a number of questions regarding ‘how to’ film vulnerable subjects and capture their biographies within the differing power relationships inherent in this endeavour; however, he sees the potential for ‘filmmaking as a way of restoring some measure of authenticity and other positive attributes to experiences that are generally devalued in our society’ (1998: 88).
Stastny (1998) also explores the challenge of being in close proximity to his subjects and the disclosure of ‘self’ within documentary practice – specifically, the folly of excluding oneself from the work when one is intimately entwined with it. In his discussion referring to autobiographical works made by persons living with psychiatric disabilities, he asserts that:

The familial, personal, and self-reflective relationships that come to life in these films are manifestations of a deconstruction that has affected the traditional subject–camera–director relationship. Aside from its ramifications for cinema in its entirety, this has a special meaning for the representation of persons with psychiatric disabilities. It indicates that the conventional distance between author and subject can be overcome, at least to a point, without undue risk of harm to either party. (1998: 87)

Further, he asserts the potential therapeutic value of video diaries by persons with psychiatric disabilities, but concedes that the:

psychiatric establishment would have to cede control over the persons experiencing altered states and allow the introduction of a subjective camera into the clinical setting (1998: 88).

It may be said that this anxiety is reflected somewhat in Hardwig’s (1997) *Stories and Their Limits*, in which he sees autobiography as ‘epistemically and morally suspect’ (1997: 50). He does assert that it remains important, but is concerned that this be ‘within narrative ethics’. He presents his argument at length, in essence challenging the singular point of view of the patient subject,
and suggests that, for example, family members’ biographies or points of view in relation to the patient undergoing examination be taken into consideration. He suggests that bioethicists and clinicians need to become biographers, bringing together the multiple narratives of others involved in their care, in a bid to furnish a fuller picture of a patient subject’s position. His argument is logical, and the notion that ‘dialogue is better than monologue’ seems to make sense. However, framed within psychiatric and intellectual disability, the idea that ‘attending to many voices is almost always morally preferable to listening to only one’ is problematic when placed within the history of disability discourse in terms of biographies of the many others and how they view the solitary voice of the ‘other’. To complicate the exchange further, this interpreter or biographer – in Hardwig’s example, the medical practitioner – brings with them their own biography, imbued with their own values and ideologies through which they see and hear their subjects’ stories.

To contextualise the potential that these practitioner biographies may have when intersecting with those of these vulnerable subjects, the following excerpts demonstrate two differing narratives, each competing for a way into our collective consciousness and conversation, creating what Buber (see Kramer, 2003) may well call opportunities in the historical moment:

The epidemiological impact of antenatal screening and subsequent prenatal diagnosis is clear with pregnancy and birth prevalence rates diverging steadily over time since the late 1980s. The rising termination rate in younger women suggests that the benefits of antenatal screening are now extending to the lower risk younger age groups. (Iliyasu et al., 2002: n.p.)
My concern here lies within the language: ‘rising termination rate’ is equated with a ‘benefit’. There appears to be an assumption here that capturing the disabled subject prior to birth has an uncontested positive effect – the phrasing of the above quote appears to naturalise the decision to terminate following a prenatal diagnosis that delivers an ‘at risk’ verdict. Further, as Moates (2002) speculates, matters of economy increasingly are impacting upon the categorisation of normal and abnormal:

Improved funding for disability services and positive information about disabilities in general would help eliminate the stigma that seems to be eroding the tolerance and generosity of society. As newer technologies emerge to screen earlier and for more differences the distinctions between what is normal and not so normal appears to be a scientific or economic decision rather than a humanitarian one. (2002: 11)

Amidst this ‘talk’, other conversations are taking place in the social arena, challenging and shaping our individual and collective decision-making and points of view. Hawthorne’s (2006) recent findings reflect changes in what being a good mother means when framed within emergent pre-natal testing technologies and disability discourse. Increasingly, and in similar trends to those identified by Rothman (1986), Browner and Press (1996), Ettore (2000) and Rapp (2000), the uptake of these technologies is being seen as ‘the thing to do’ – as natural. The results delivered are immutable and scientifically sound, and to continue with a pregnancy resulting in the birth of a person with a disability is seen as economically irresponsible and in direct contradiction to
what being a good mother is supposed to be – ensuring a child has quality of life (Hawthorne, 2006). Certainly for me, Buber’s notion of the human world being ‘split into two camps’ resonates here (Buber, in Arnett, 1986: 28)

Within this fragmentation in disability and medical scholarship, parallels can be drawn with feminist inquiry, wherein much contestation of the category of ‘woman’ has been seen. As Gilmore (1994) states in her work examining women’s self-representation:

> The differences are for women so pervasive, specific and significant to both political and aesthetic interpretations that any effort to consolidate ‘women’ as a unified group risks homogenizing differences. (1994: x)

Such is the challenge for those living with disability. I have felt many times that embarking upon this project was at best hazardous, with the many viewpoints, contradictions and questions implicit in representing disability further complicated by my close proximity to the people for whom I was wishing to advocate.

Gilmore’s notion of finding my way ‘by making a map for getting lost’ (1994: 39) resonated often. I have endeavoured to capture this idea in the film, with voiceover narration as well as some humorous moments captured on camera when I did actually ‘get us lost’. I have endeavoured to bring this notion of getting lost into the film, not only to mirror my own difficulty with charting new ways of being, but also to challenge ‘what is known’ via our DNA and bringing
people to the screen who simultaneously personify and defy the mapping of our molecular structure.

Capturing these moments and playing them back in the edit suite, I was often times struck by how often Dessaix’s ‘irony of circumstance’ came into play as I began to see storylines emerge that were ‘mysteriously knotting, branching and forming together’ (1994: 188). Bringing these moments together in creating this film, amidst what I hope has been demonstrated in the preceding discussion of disability and autobiography to be a veritable minefield of opinion, perspective, ideology and lived experience, has been challenging to say the least. I have attempted to create a piece emulating’s ‘between’ – looking for answers somewhere in between the theoretical and the lived, the abled and the disabled, the individual and the collective, that might invoke conversation and discussion about who we are as a society and how we wish to move forward and shape ourselves. Buber’s emphasis on community as emergent between persons, fuelled by ideas responsive to the historical moment (in Arnett, 1996: 134) is timely in terms of how we view disability and how we navigate our future with technologies that define life before it begins, within the binaries of ‘normal and abnormal’, as well as whose autobiographies and biographies are privileged over those of another.

The autobiographical choice in this instance came from my desire to communicate and connect with an audience, and take them with me on a journey of discovery. This approach seemed to bridge the ‘gap’ I believe existed in the work in its initial stages. Attempting to introduce an under-
reported medical condition required some exposition; however, from my perspective, to have maintained my distance and sustained an expositional approach would have lacked the intimacy I was keen to invoke in the film. I have endeavoured within this approach to give voice to the many rather than the one in answer to Mitchell’s (2000) concerns, but as much as has been possible within this work, I have tried to provide the space for individuals to tell their own stories in a similar fashion to *Count Us In* (Kingsley et al., 2007) so that their experiences are inscribed in the piece.

The inclusion of many voices thus succeeds in creating a series of micro-narratives of individual experience intersecting with ours and demonstrating the vast spectrum of conditions associated with Chromosome 18 differences. By so doing, it seeks to challenge the very broad categorisation known as disability. Through exploring these narratives and ‘inviting’ an audience to get to know our community, my ultimate goal is to challenge the ways in which a molecular analysis defines normal and expectations around what ‘quality’ of life constitutes, and how that is defined. For me, it is ‘unknowable’, and much within the medical discourse regarding elements of ‘risk’ and ‘benefit’ is in urgent need of contestation.

To the casual or the inquisitive viewer, it may not be immediately evident that the film is steeped in political intent; however, located within the various frameworks discussed here and placed within the historical act of self-authorship within oppressed minorities, the very act of picking up the camera, together with my role as Allycia’s advocate, is indeed political. This is hardly a
new phenomenon within the history of documentary film; hence I now turn my attention to a discussion of the theoretical frameworks implicit in making a documentary film, the practitioners of the craft who have influenced my practice and how I have translated these learnings into my own.
4

Documentary Theory and Practice

I write and make films, because I have to explain certain experiences to myself and others. I have to explain human actions and reactions. Working is the working out of something.

- Helena Sanders-Brahms

Prolific filmmaker Helma Sanders-Brahms unashamedly brought both her own story and those of others to the screen in a time when women of the West were collectively taking up the challenge of bringing their stories forward in new and powerful ways. As I first began researching film and theory, her motivations for telling the numerous stories she has fashioned resonated with me, particularly her own unique autobiographical film, Germany, Pale Mother (1980), a work made about her own childhood for her daughter. The idea of ‘the working out of something’ certainly reflected one of the primary drives and questions at the centre of my work. Why was it that I felt compelled to advocate for my daughter and her community, in order to assert the value of their lives? Certainly, in the early stages of the project, frustration and anger fuelled a desire for our community to be seen and heard, but my instinct was that our experiences were not unique. I believe our community has much to offer the wider community – an idea that stands in stark contrast to the notion of burden so entwined in the narratives that have shaped the historical and contemporary representation of disability.
In my mind, the work, my desire, sat well within Nichols’ (1991) impulse and tradition of documentary film, particularly his assertion that the ‘pleasure and appeal’ of the medium lies ‘in its ability to make us see timely issues in need of attention, literally’ (1991: ix). In terms of the myriad issues facing people living with disability, I felt that my concerns went beyond myself and my family. Universally, we are – and have been for quite some time – in need of some attention. Within the tradition of the social documentary, the work is a ‘creative treatment of actuality’ – the phrase coined by Grierson (1932), credited with being the originator of the West’s documentary form as we know it today. My hope was that in documenting our experiences I could access the medium’s ‘ability to open our eyes to worlds available to us, but for one reason or another, not perceived’ (Barnouw, 1993: 3).

The world I have endeavoured to represent in the piece can only ever reflect nuances of the vibrant, diverse and different lives we have as a consequence of being delivered our sometimes frail but often resilient children. The film, too, can only hope to show fragments of and glimpses into the way in which my view of the world has changed. So, in many respects, representation can only ever aspire to opening up windows to worlds we have yet to discover – and a journey with a person born with significant intellectual difference is certainly a venture into the unknown. Yet we continue to place our faith in others, experts, the educated, to direct us either towards or away from the unknown, in spite of the reality that they, in many respects, know only as much, or in some cases less, then we as parents know. The film, then, is really an invitation to begin to explore the largely unknown world of Chromosome 18 difference in particular,
and the world of disability in general. This chapter discusses the influences, theoretical frameworks and challenges involved in creating this visual invitation, and includes some personal reflection on the marked differences to my approach to the portrayal of disability in fiction as opposed to documentary film. The strength of the film is not in its technical prowess, for the astute filmmaker and audience will soon identify the flaws, nor does it lay in the fashioning of a new mode of documentary filmmaking per se. Rather, the strength is in the characters and their spontaneity – those moments captured that can never be ‘recaptured’, and the frankness and honesty of the people who have had the courage to allow the camera to be a conduit for their stories, our stories.

**The Production and Re-production of Disability**

*Give us adequate images. We lack adequate images. Our civilization does not have adequate images. And I think a civilization is doomed or is going to die out like dinosaurs if it doesn't develop an adequate language for adequate images.*

- Werner Herzog

The chapter – and in a sense this thesis as a whole – is really a discussion based on Fabian’s (1971) fundamental principles, as explored by Ruby (1980) (see Figure 4.1). In accordance with Ruby’s suggestion, I have added the audience as a key factor in the production of my film.
The film and the thesis, being the *products*, have been created via the *processes* of documentary filmmaking and academic research. The preceding chapters, and indeed the film, disclose much about me as *producer*, in laying bare my motivations and my context, with this chapter now furnishing the key influences and film production practices that have succeeded in shaping the work. While the above diagram connotes a simplicity of sorts, the process of bringing this film to fruition can hardly be described as a simple or easy endeavour, and by necessity includes my assumptions and beliefs about what an imagined audience might experience when viewing the work.

I have been mindful of attempting to remember ‘who’ I was at the time we were given Allycia’s diagnosis – generally speaking, while I certainly had contact with persons living with disability, I really had very little idea of their experiences; I was to all intents and purposes ‘outside’ the experience of living with disability. I have endeavoured to place myself as an inquisitive outsider to disability in terms of lack of knowledge and isolation in a bid to ‘bring’ an
audience with me as I discover more about the condition and meet others living with disability.

The worlds of those born with disability, when they have been made visible, have been misconstrued, misunderstood and under-valued (Mitchell and Snyder, 2000, 1996; Barnes, 1992; Norden, 1994; Darke, 1999; Green and Tanners, 2009). Such image-making and representation has succeeded in diminishing the worth of persons of difference to those in the wider community. I began to wonder where these ideas and attitudes about people who are born outside the ‘average markers’ of normal might have come from. In truth, I hadn’t given much thought to disability and what it meant until Allycia was born, so I was in fact asking those same questions of myself. Where had my ideas about disability originated? How had my ideas about normal and abnormal been forged? Even more disconcerting was the knowledge that these markers, the genetic blueprint for what normal is deemed to be, were becoming indicators for whether pregnancies would continue. On what premise, outside cellular analysis, were these decisions being made? This became a burning question for me, particularly when so little is known about conditions such as Allycia’s.

In light of the limited information given to me with the genetic testing results I received about Allycia, I felt that a number of issues needed to be addressed for prospective parents and professionals, as well as the general public – I was looking for a way of inviting the outside in. In the absence of a body of work dedicated to ‘what’ life living with Chromosome 18 anomalies might ‘be like’
and the use of the words retarded, impaired, disabled and abnormal accompanying a genetic analysis, I believed it was important to create a credible work documenting the potentialities of persons with the condition and how their families change and grow when embracing life with persons of difference.

The potentiality of people categorised as retarded, impaired, disabled and abnormal is rarely captured in what I choose to call the ‘fullness’ of their experience and, as discussed in Chapter 2, the portrayal of disablement and impairment, when viewed historically in both fictional and non-fictional works, has been problematic to say the least. This diminishing of worth now has moved beyond or before birth – the potentiality or viability of life can now apparently be determined beneath a microscope.

These results, the verdicts gleaned from these technologies, are not delivered in a vacuum, but rather are laden with medicalised vocabulary imbued with notions of risk, signalling the viability of the unborn foetus and the quality of life the foetus can expect to have. A vacuum does exist, however – particularly in the realm of rare genetic disorders – in terms of the paucity of experiential evidence of the potentiality of these supposed defective foetuses; until recently, there have been few resources available so parents-to-be can, at the very least, view accounts of what life might be like for and with a person of difference.
As this project draws to an end, this situation has certainly changed radically, in no small part due to the advent of the internet and the availability of more accessible technologies for individuals and groups to record and upload visual accounts of their experiences. (The Chromosome 18 site has certainly evolved over the last five years from a text-based informational site to one that is rich with personal accounts and extensive research information.) This was not the case in 1995, when Allycia was born. Further complicating this exchange of information between the medical specialist and/or genetic counsellor and the prospective parents is the notion of stigma, together with the societal and cultural values and ideas operating in individuals’ spheres of experience.

Hawthorne (2006), in her research exploring the uptake of pre-natal technologies, furnishes a discussion identifying the many influences that come into play for mothers prior to and following the use of these technologies. She, too, explores the notion of what being ‘a good mother’ has come to mean amidst the uptake of predictive procedures, with a number of significant indicators that are pertinent to this work. Hawthorne’s work reveals that contemporary views about ‘being a good mother’ – including garnering knowledge, minimising risk, minimising pain and suffering for one’s offspring, admitting one’s own inability to raise a child with disability, and a hierarchy of disability – seem to be emerging, creating a situation where physical disability may be acceptable; however, cognitive disability is seen as far more problematic in terms of a child reaching his or her full potential. There is a distinct lack of addressing ‘who’ this person might become, and this question is
raised at the beginning of my film, systematically working towards meeting the many ‘whos’ of the Chromosome 18 community.

For me at least – and I believe for disability universally – this apparent denial of a ‘who’ in the medical discourse, and the delivery of so-called knowledge, demand other points of view – or what might be framed as Deleuze and Guattari’s ‘alternate lines of flight’ (1987). The offering of a ‘different kind of normal’ endeavours to show the differences that have evolved and emerged in our lives since Allicia’s birth, as well as other families’ accounts and experiences, showing some of the challenges we face as well as all that is ‘here’ to be embraced, enriched by and celebrated. It has been my goal to create a work aspiring to Williams’ (2005) notion of presenting ‘life not only as it is, but rather a deeper investigation of how it became as it is’ (2005: 66). As she posits:

the truth figured by documentary cannot be a simple unmasking or reflection. It is a careful construction, an intervention in the politics and the semiotics of representation. (2005: 72)

Williams articulates the challenge for myself and those concerned with representing disability to an unknowing public as follows:

If photographs and moving images are not mirrors with memories, if they are more, as Baudrillard has suggested, like a hall of mirrors, then our best response to this crisis of representation might be to do what Lanzmann and Morris do: to deploy the many facets of these mirrors to reveal the seduction of lies. (2005: 72)
This production does not necessarily sit within a revelatory mode. However, in terms of a thorough investigation into the history of disability and a delving into how and why society may have constructed the category of disability, the ways in which I and other parents re-produce and refigure meaning within the context of our lives with children with physical and intellectual impairment is revealed in the film through personal interviews, as individual journeys of discovery are retraced. The difficulty with bringing these stories to the screen is that they are primarily internal journeys – journeys of the heart and mind – that do not necessarily have accessible visual counterparts; hence the interview has played a major part in the film.

Filming the interviews with adequate lighting, high-quality sound and a pleasing aesthetic proved to be challenging in most instances, as the majority of interviews were recorded ‘on the run’ at conferences where access to all of the above was problematic within the confines of noisy hotel spaces surrounded by many conference participants. Added to this, the tyranny of time and distance impacted upon acquiring the interviews within the parameters of the three-day limit in Plymouth that included recording panel sessions, meeting prospective interviewees who felt comfortable about sharing their stories with a relative stranger, building relationships, recording interviews and catching glimpses of the general interplay of our community with a very patient ten-year-old Allycia by my side.
Despite meeting people who were happy to share their stories, the interviews shot in Plymouth were particularly problematic in terms of sound quality, due to my microphone, boom and sound having been left behind in New York. In retrospect, it may well have added to some of my mishaps in the film to have recorded these instances as an homage to one of my influences in my documentary film practice, Ross McElwee.

I have worked with two editors during the project, Tfer Mader (who is also the sound designer) for the first two years and Nicole Bourke, who has brought the film home. I have been unable to offer either woman a great deal by way of remuneration due to the financial constraints of producing a film in the academic rather than commercial realm; hence our work has been conducted alongside our paid working lives, which presented a host of difficulties in aligning our busy day-to-day schedules. Martha Goddard and Rebecca Richardson have also weighed in at various junctures, and added insight to the film as it is today. It has been vital, in my opinion, to work with an editor as a person who sits outside the film, given my close proximity to the work. They have brought much to the work by way of technical expertise and critique, and have both challenged and supported my process, as required at the time. The many hours that animator Paul van (awesome) Opdenbosch devoted to the crafting of the animated sequences seen in the film were contributed in between his work and family life. With minimal funding and the ensuing difficulties in acquiring adequate support personnel for lighting and sound particularly, it has been quite a challenge to capture the highest quality imagery.
and sound for the work; however, the content brings much to the fore in terms of laying bare the different kind of normal we experience in our lives.

The arduous five years devoted to this work and the 100 hours of footage taken will not be apparent to most after viewing the film. To this end, I will discuss my approaches – which may be seen as a justification of sorts for the lengthy time and processes that have shaped the final piece. I trust that this justification will offer some insight into the challenges that have confronted me in bringing the work to completion.

Reflecting Back, Moving Forward: Theoretical Frameworks and Aesthetic Aspiration

Above all, documentary must reflect the problems and realities of the present. It cannot regret the past; it is dangerous to prophesy the future... Rather it is contemporary fact and event expressed in relation to human associations.

- Paul Rotha

The history of what we, in the West, have come to know as the documentary film is rich in content, approach and form, as demonstrated in Ellis and McLane’s, *A New History of Documentary Film* (2005), an extensive overview, and in specific examinations of culturally specific developments, such as Harvey O’Brien’s *The Real Ireland* (2005). The level of academic critique and
debate that exists surrounding the documentary form’s supposed objective and authoritative nature versus notions of subjectivity and bias is just as rich.

18q: A Different Kind of Normal makes no claim about, or any apology for, the subjective positioning of the material presented – it is, after all, an autobiographical work. There is a claim to a degree of knowledge; however, the subjective far outweighs the objective – I have an opinion, and I began with a point of view and a vision I wanted to bring to life. In many respects, had I relied on fact and objectivity, there may not have been a great deal to talk about, and the work that has emerged – had it emerged – certainly would have taken a markedly different direction.

I have chosen to base my discussion of the theoretical on Nichols’ (1991) frameworks, primarily for simplicity’s sake and because these provided the foundation of my own learning. However, I acknowledge that this approach is increasingly being contested, as writers such as Bruzzi (2000) challenge their genealogy and categorisation of the expositional, observational, interactive, performative and reflexive as distinct categories amidst new, emergent documentary forms which embrace the craft’s traditions as well as the increased visibility and inclusion of the filmmaker in the work. The emergence of autobiographical documentaries in the 1970s, and approaches taken by contemporary filmmakers such as Nick Broomfield and Michael Moore, have had the effect of further problematising and defying distinct categorisation.
In some respects, *18q*: *A Different Kind of Normal* reflects many of the assertions proffered by Bruzzi (2000). My narration, for example, has many functions other than a strict adherence to the ‘voice of God’ approach that traditionally has defined the expositional. This is not to say that the film does not borrow from the traditions that have laid the foundations for the many and varied documentary films prevalent today, and in terms of the expositional the influence of earlier documentarians such as Grierson and Flaherty (Nichols, 1991: 32–3) can be seen. Just as these works presented particular world histories with an air of authority and ‘voice of God’ commentary, this film required the delivery of new knowledge to establish our place in the world. Bringing a group of people whose community has been built upon their genetic analysis, and who remain ‘unknown’ in the public sphere, requires backgrounding and explanation. Genetics and medicine may be viewed as complex sciences requiring exposition and narration; however, within this work the medical knowledge is delivered primarily by parents, carers and individuals, rather than a removed, expert, aloof voice.

Elements of the observational and interactive are present alongside the expository approach; however, it probably sits most ‘comfortably’ within Nichols’ (1991) representational modes as a reflexive work. The observational mode pioneered by filmmakers such as Wiseman and Leacock is reflected throughout the work, most specifically when the camera has been turned towards Allicia in medical and educational settings. The history of the observational form in presenting those ‘othered’ members of society is, however, chequered with dispute and disrepute. For example, Brian Winston

In reply to Winston’s question, *18q*: A Different Kind of Normal seeks to ‘fill in some gaps’ in filmic works addressing disability – ‘gaps’ that are concerned with the delight that can be experienced when living in the world with a difference in intellect and perception. It is the meaningfulness of lives lived with disability that is my concern.

While the film addresses issues that are disturbing, it is hoped that it will add to the conversation about a meaningful life lived with and by people with disability, and reflect more ‘positive’ images and experiences of those people. The inclusion of ‘positive’ images does not necessarily include images of people living with a disability doing ‘normal things’ or ‘being normal’; rather, the inclusion of images that refract the ‘normal’ and offer alternate readings about humans ‘being’ is intended to reflect Adorno’s notion of mimesis, articulated by Brunkhorst (1999) as:

an attitude to one’s natural and social environment and to other people and other things that does not compel this otherness to be under one’s own will. Mimesis in the sense Adorno is using the word here means to do justice to the otherness of the other, and to react adequately to the latter’s own aptitudes
and concerns. False projection. Conversely means the projection of an image that does not fit with the otherness of the other, one’s own egocentric image of the world. False projection makes everything its own image. (1999: 62)

From this standpoint, the work succeeds in terms of Fredriksson’s (2010) summation of Adorno’s aesthetics in that ‘works of art are not to be observed or interpreted. It is the other way around. Ideally, film helps us understand ourselves, the work of art interprets us.’ (2010: 12)

Observing myself has been quite a different challenge, and in the final cut the footage that could have been termed ‘observation of self’ was discarded. Those times when I turned the camera upon myself, by myself, did not serve the overall intent of the film. In truth – my truth – the footage captured when I did turn the camera upon myself appeared to me to be either awkward or self-indulgent and rambling. On several occasions, the camera captured moments of my frailty, vulnerability and delight when it was placed in the hands of another and I was ‘free’ to be observed. On other occasions, watching the footage back, I have been aware of my own awareness of the camera’s presence, and while I have chosen – together with my editor – to include some of these moments, they have been included to serve the need of the film – to develop character and relationship – rather than to serve its intent. My choice – which I have endeavoured to make clear in this written account of process thus far – would have been to remain invisible, which in itself may well be fodder for another thesis. However, I had made the commitment to reveal certain aspects of our lives, in order that what I perceived to be a greater need for a more
universal revelation of how being categorised as disabled could be laid bare for examination and discussion by those who viewed the work.

The film features many interviews – primarily with individuals and families whose lives are affected by Chromosome 18 conditions – utilising the interactive modality pioneered by filmmakers such as Jean Rouche and Connie Field, wherein the subjects are invited to share their perspectives in tandem with the interviewer. The inclusion of interviews with those ‘outside’ the story, and others with expert opinions, serves a number of functions. These voices – including Allycia’s teachers, a disability activist, one of Allycia’s doctors and fashion photographer Rick Guidotti, featured sitting ‘alongside’ the Chromosome 18 ‘voice’ – furnish further knowledge and are included in the film to introduce perspectives that add to our story by furnishing ideas about disability and experience with disability, giving an audience ‘outside’ our world other points of view.

Apart from those occasions when I am in front of the camera, it is apparent to an audience that it is me asking the questions, and by inference that there are particular reasons for those questions. The nature of the information imparted in these interviews reveals much about where I have found myself in the past and some of my fears for our future. Myself – the ‘I’, the filmmaker and sometimes subject – is always ‘there’: my questioning, my experiences, my voice, are ever-present. Thus the reflexive nature of the work is apparent, revealing much of myself; however, as shown within Ruby’s (1980) articulation, in this modality much remains concealed.
While documentary theory defines these modes and approaches to directorial choices in order to study, analyse and teach aspects of the craft, contemporary practices do indeed reflect Bruzzi’s (2000) assertion of the tendency to combine those modes. In practice, this has been my experience, having also been influenced by practices that began to emerge in the 1970s, with women bringing forth a plethora of autobiographical works crafting visual accounts of the world around them. McElwee, too, in his approach and self-characterisation embracing levels of ineptitude, has influenced the shaping of my character in the final cut – although, ironically, the footage and circumstances that succeeded here were not constructed, but rather happened quite accidentally.

Michael Moore influenced my thinking about the function of documentary in addressing social issues. His technique of bringing issues of inequality and power differentials to an audience’s attention in Roger and Me (1989) by, for example, using traditional documentary approaches alongside his unique and provocative persona in asserting a very definite point of view, has been a highly successful strategy. My intent here is not dissimilar, but my approach is markedly different from that of Moore. While I have opinions about the value of persons of difference, and work towards contesting the construction of disability as undesirable, I did not set out to present a point of view that was uncontested. The fact that we as a family became separated due to financial and economic difficulties, which were in part due to the circumstances of us caring for Allycia, with the extra needs she has, is shown in the film, and defies a sugar-coated version that all is wonderful in the world of disability. So too,
Tameka’s short-lived, pain-stricken life, and Irene and Scott’s story involving the birth of two of their children with the condition, act to furnish a fuller picture of the difficulties that are encountered when living with Chromosome 18 anomalies.

My intent is to provoke discussion around how we evaluate the viability of unborn foetuses, and show how we embrace the challenges and the joys that are part of life with what we currently call disability, just as they are part of life without it. This intent is brought forth by the sharing of stories and by reflecting on how individuals and families have found their way with their new lives.

Such intent needed to be founded in disclosing new knowledge due to the condition being largely unknown. Here, I found inspiration in another highly successful contemporary documentary film. Little academic attention has been turned towards *What the Bleep Do We Know!?* (Arntz and Chase, 2004), but the use of highly stylised computer-generated images to heighten the portrayal of the internal versus external worlds explored in the film was, in my opinion, an effective device. The 3D animation created by Paul Van Opdenbosch for *18q-: A Different Kind of Normal* (see Figure 4.2) was not intended to emulate the very complex images seen in *What the Bleep Do We Know!?*, nor was it crafted to necessarily represent accurate scientific imagery of our inner worlds. It is a creative treatment of the chromosomes and DNA, and therefore not intended to be a true representation in the scientific sense. Rather, it has been created to provide vision for the explanation of the condition, and represents a world removed and ‘unknowable’, as opposed to the living, breathing human
beings experiencing their lives with Chromosome 18 anomalies. The sequence is used as a backdrop intermittently, as a motif signifying the ever-present reality of living with genetic difference. It also features throughout the film as the background for interviewee title cards, and is used as a visual backdrop for the text listing the various physical manifestations of the condition, juxtaposed with home-style photographic stills of Allycia and her siblings growing up together. This device illustrates the distinct difference between the medical text, the microscopic DNA and the living, breathing joyful child Allycia has become.

Source: Animations created by Paul Van Opdenbosch.

Figure 4.2: Animation frame used throughout the film

In many respects, the work embraces an anthropological approach, as a small group of people living with a rare condition are given form and voice where previously there was none. My ultimate desire is that the film reflects esteemed
documentary filmmaker Marlon Rigg’s interpretation of anthropology as being an ‘unending search for what is utterly precious’ (*Tongues Untied*, 1990).

With the delivery of this information of an unknown medical condition comes an invitation intrinsic to documentary filmmaking: a fascination with the out of the ordinary. While this endeavour was a new experience for me, the documenting and capturing of images:

as ways of recording, exploring, investigating, educating and enlightening is hardly a new phenomenon, beginning with the advent of the moving image documentary with Edison’s Kinetoscope in 1894 and Lumière’s Cinématographe in 1895. (Wain, 2007)

Their ingenuity paved the way for medicalised film and artistic collaborations in 1905 with avant-garde teacher Arthur Van Gehuchten (Chio et al., 2003), and for the work of Camillo Negro and filmmaker Roberto Omegna in 1908 (Galloni, 2002). Needless to say, the rest is history, with the form of film discussed here being shaped by the technologies of subsequent generations, the collective inquisitive nature of our humanity and a drive to illuminate and educate audiences about the myriad issues facing society through the years. It is something of an irony that creating this work occurred in defiance of what appears to me to be the very beginnings of the form where scientific inquiry and the promise of capturing knowledge were entwined with documenting fact. Here I hope to challenge medical fact delivered in isolation from the stories of those persons who are living with the many manifestations of genetic difference captured by the gaze of the medical lens framing them.
In bringing those stories to life, structuring the film has been extremely difficult. The film has undergone some marked transformations with each successive cut, as I have worked towards creating a piece that not only imparts information but endeavours to connect and resonate with an audience at an emotional level. Obeying narrative conventions underpinning fictional and non-fictional storytelling was key in terms of an audience being able to access the film easily, and structuring a piece within the traditional three-act mode was proving to be a challenge prior to the international conference we attended in 2007, which succeeded in giving me an outcome with which I was happy – not only for the film but, more importantly, for Allycia and me.

In this struggle for story, I spent many hours examining other documentaries, with *My Flesh and Blood* (2003), *Murderball* (2005) and *Tarnation* (2003) significantly influencing my work. These films are varied in both content and approach, but shaped my film significantly by demonstrating practices that I would eventually find effective – or not.

*My Flesh and Blood, Murderball and Tarnation* all enjoyed success at the box office. Each film explores disability within a different context, and demonstrates a different narrative approach. *My Flesh and Blood* opens the door on a unique single-parent family, where Annette Tom takes care of a number of children she has fostered. The children, apart from her biological daughters, all have significant disabilities. The film is structured using the change of seasons as transitional elements between various sequences, and features some of the
everyday, sometimes delightful, sometimes gut-wrenching experiences through which the family lives. While I admired Annette and was in awe of her ability to manage the many demands of her life, I felt that she was far more saintly than I – I found myself lacking and wanting when I compared the person I think I am with the character I saw on screen. My intent was to challenge phrases such as ‘only special people are given special children’, which have often been thrown my way. If people are to make decisions about becoming a parent of a person with a disability, placing parents and carers in unreachable heroic positions does not, in my opinion, give a true account of how life plays out. We parents are flawed and sometimes frail, and certainly have bad days; however, I do recall that my own parents did too, I did not have siblings who identified as ‘abnormal’.

I did endeavour in an earlier cut to emulate the structuring of My Flesh and Blood (2003) in my work by using the children’s nursery rhyme, ‘Saturday’s Child’ (author unknown) as a thematic device. With each day of the week coupled with a particular quality, the cut was divided into seven segments addressing issues such as being ‘full of grace’ or ‘fair of face’. The cut worked to a degree, but felt somewhat contrived, and I believe still mirrored a significant distance between we in the film and the audience. It was as if the use of text and storytelling devices took away from the closer connection I was endeavouring to capture, so this strategy was in the end discarded.

Murderball (2005), which follows the lead-up to the United States–Canada clash at the national ‘Murderball’ championships, was for me a riveting film,
challenging notions of men in wheelchairs lacking masculinity. The film presents some engaging personality clashes and personal stories of challenge and forgiveness. At times, *Murderball* is gritty and confronting, and while I enjoyed the film, it dealt with physical disability in the adult world, and the ‘in your face’, raw approach was not one that sat well with the intent of my own work.

Released in 2003, *Tarnation* – an autobiographical documentary – offered yet another approach to disability, with notions of the ‘other’ and mental illness explored by filmmaker Jon Caouette. The film was lauded by critics and again was one I enjoyed immensely. However, the creative approaches used, which worked well within the context of Caouette’s work, did not lend themselves to *18q*: *A Different Kind of Normal*. Caouette’s persona, captured throughout the years as he filmed himself at various times in various guises, was intriguing and the film demonstrated a great deal of honesty and transparency – qualities I hoped would shine through in my work.

*Murderball* and *Tarnation*, while powerful in their own right and sitting within the genre of documentary, biography and autobiography, deal with significantly different experiences of disability and otherness, signalling the diversity of *disability* as a multi-faceted category. I felt I needed to be much gentler in my intent – I was, after all, dealing with my young children, family and friends. I believe my work will be of interest to parents of children with disability, and as I recalled the fragility of my state of mind and bewilderment at the time of Allycia’s surgery and subsequent diagnosis, I wanted to deliver a piece that
demonstrated hope and joy amidst the many challenges that can be faced by those living with Chromosome 18 anomalies.

From this point of view, fictional film also has played a significant role in my practice in terms of storytelling devices, and while theorists cite these approaches as significant in new emergent documentaries, re-enactments ‘are hardly ‘new’ – for example, they hark back to Robert J. Flaherty’s *Nanook of the North* (1922). Those most influential in terms of my practice and this film are *The Other Sister* (1999) *What’s Eating Gilbert Grape* (1994), *Forrest Gump* (1994) and *I am Sam* (2001).

*I am Sam* touched me deeply in terms of Sean Penn’s character prompting my imagining of Allycia’s life as an adult – how will Allycia chart her life and how would the arrival of a child in her own life impact upon her? These are questions that I am unable to answer at this time. One of the most significant aspects of this film for me is the subtlety of the mirroring of the mannerisms the two central characters, played by Sean Penn and Michelle Pfeiffer, deliver in their performance. As a high-powered lawyer with poise and stature when placed under stress, Pfeiffer demonstrates similar mannerisms to those delivered in Penn’s performance as intellectually impaired Sam. I have endeavoured to capture mine and Allycia’s similarities with a number of shots in the film, most particularly in the closing scenes. From my perspective, and as one of the central themes in the film, the ideas of genetic difference and pre-natal diagnosis are challenged somewhat by endeavouring to show these similarities (see Figure 4.3).
In *The Other Sister* (1999), Diane Keaton’s role as mother confronted me with my own need to control Allycia’s environment and my fears for her future. In the sequence where I break down while we are moving house, these fears are laid bare before the camera when my defences are down and my own sense of powerlessness is apparent. In some respects, meeting the young adult couples in the United States provided an answer to this fear, as it enabled me to see possibilities for Allycia’s future become manifest in the way the young adults are forging ahead with their lives.

*Forrest Gump* (1994) both inspired me and brought me to tears. The character’s beauty, his unassuming nature, and his ability to take life in his stride and ‘know’ who he was in the world encouraged me to remove the limitations that were constantly thrown my way in terms of Allycia’s potentiality.
within medical diagnoses. Sally Field’s portrayal as Forrest’s mother was timely, and her desire to see Forrest find success in his life bolstered my determination to help forge paths for Allicia – although thankfully I have not yet had to exchange sexual favours to ensure Allicia’s enrolment in school. The difficulties and discomfort Allicia has experienced with her feet, and her triumph in achieving her dancing trophies – although quite coincidental – may be seen to align with Forrest’s journey. In terms of borrowing approaches, as a filmmaker I particularly liked the use of the feather on the gentle breeze that opens and closes *Forrest Gump*; it inspired my use of the rainbow spiral helix at the beginning and end of my film. The helix image also serves as a motif of the interplay of the DNA and the person it presupposes. At the beginning of the film, a dissolve from the rainbow helix mobile that Allicia and I hang up together to the animated helix is designed to bring the two worlds – our lived experience and the medicalised condition – together in a new way, one that is filled with promise and hope, as captured by the rainbow colours of the mobile.

In the closing sequence of the film, the tail of a rainbow-coloured kite with which Allicia and I are playing becomes snagged – a serendipitous moment, akin to Ascher’s trapped cat on the roof sequence in *Troublesome Creek* (1995) – and then is freed to fly, dissolving back to the rainbow helix that opened the film (Figure 4.4) and closing with an animated helix.
Viewing *What's Eating Gilbert Grape* (1994) was significant because it showed the role of sibling as carer and the difficulties that are encountered along the
way for the carer as they endeavour to meet their own and their affected sibling’s needs. For me, the eventual death of the mother and the torching of the house were symbolic of the need to let go of all that is known and re-imagine a new way. 18q-: A Different Kind of Normal is essentially a film about letting go of the known and embracing the unknown.

While fictional films dealing with disability have come under significant criticism for their stereotypical portrayals and the use of disability as a short-cut for metaphor, films such as these do have value, and were of particular significance to me in the absence of access to shared progressive narratives of others living with Chromosome 18 until Allynia was ten years old. The other value of these types of inspirational stories – although critics may not necessarily agree – is that these tales opened doors for me to re-imagine life against the bleak outlook offered by medical discourse.

The influence of these films on my life, and on my professional practice, may not be particularly sophisticated when placed alongside the writings of the film critic or the academic; however, I have included them in a bid to demonstrate the part that I believe fictional film can play in the re-imagining of life with disability – particularly in the realm of rare conditions where few have travelled before and new stories are yet to be forged as we continue to find a place for our children and adults in society today. When viewed historically, recent history shows that it is only since the dismantling of government institutions for those living with disability that we have been involved collectively in these new journeys of and with people of difference.
Upon diagnosis of conditions such as Allycia’s, I believe – and it has certainly been my experience – that imaginings we have as expectant parents do not include negotiating our way through pain and grief; rather, we imagine celebrating the birth of a healthy and ‘normal’ child. With the diagnoses handed to us, we are cautioned about what lies ahead of us – ‘worst-case scenarios’, as one of the fathers featured in my film states – and so in forging forward to the fullness of life, we as parents are in fact challenged to re-imagine notions of happiness and family life.

The other fictional element, of course, is the creation of the animation. In concluding this section, I will turn to another, very different, example of animation dealing with disability – Adam Elliot’s award-winning animated film *Harvie Krumpet* (2003). The beauty of this work for me is articulated by Goggin and Newell (2005) in their analysis of the many faces of disability presented by this work. Harvie, a most endearing character at the centre of a story that is beautifully crafted, touches on many issues with humour and delicacy, and the film is a joy to watch. The need for humans to connect with one another, the way humanity is discarded when misunderstood, and Harvie’s resilience and exercising of his individuality with his final nudist jaunt are constructed with care and insight.

This is where I believe animation and fictional accounts of the disability experience can in some respects potentially triumph over the documentary in challenging entrenched ideas about what it means to live with disability. An
example close to my heart may in some way go towards illustrating why I see fictional film as a worthwhile mode of addressing some aspects of disability. In our family, we affectionately refer to Allycia as ‘the nudist’ – she once packed her small kindy case when she decided she no longer liked the rest of us and proceeded to leave via the front door wearing only a t-shirt as her round little bottom disappeared through the door. Allicya’s spontaneity and lack of inhibition are a constant source of delight to me, but as both filmmaker and her mother, I would not be comfortable about filming these moments and placing her ‘on show’. These are private, personal moments, and the decision to share them is not mine alone to make. Allicya’s awareness grows daily, and although she is still uninhibited in her choice of attire (or lack of) at home, there may come a day when that changes and I would not wish for her to feel that I had not respected her right to privacy.

While I have a passion for the documentary form and the many and varied shapes, forms and hybrids now populating the genre, as a filmmaker I have found that Sanders Brahms’ notion of ‘working through’ emotions at a personal level has best been served in the fictional realm. The writing and production of Through Different Eyes (2005) and Shorn (2006) allowed me to work through some of my experiences since Allicya’s birth in a vastly different manner to 18q:- A Different Kind of Normal. The films were expressions of the way I saw the world at different points in my life, and in some respects how I came to terms with the new life we were making for ourselves. They were also a celebration (although this may well not be evident) of that new life.
Through Different Eyes (2005) has a distinct connection with my experience of watching Allycia during the course of her heart surgery, and the confusion I felt at the time. Dealing with notions of organ transplants and donors, the film is a very black take on the desire to sustain the life of a loved one at any cost, and the dire circumstances that may follow. The image of Allycia with her chest cut open as the surgeon sought to repair her heart was life-changing—necessary but brutal. Through Different Eyes works with that brutality, confusion and human desire to privilege one life over another. The imagery in the film is confronting at times, and certainly this approach would not have served 18q:- A Different Kind of Normal.

Source: Image by David Rusanow.

Figure 4.6: Still from Through Different Eyes – Ray Sinclair as ‘The Butcher’

Shorn (2006), an Australian take on a spaghetti Western spoof with a twist, reflected another juncture along the way as I struggled with the desire to
protect Allycia, as she grew, from the sometimes cruel ways in which disability can bring vulnerability to our lives through the actions of others. Upon reflection, *Shorn* was a kind of working out of vulnerability with the hope that goodness and justice might prevail – but in a very black kind of way. These films actually facilitated a working through of my anger and confusion, and at the same time were occasions for Garland-Thomson’s ‘exuberant flourishing’ – particularly with *Shorn*, as both my daughters appeared in the film. I have included behind-the-scenes footage from *Shorn*, as well as excerpts of the final cut, in the documentary as a means of demonstrating the ways in which life takes unexpected turns and to show my family’s and my own progression in our lives.

![Figure 4.7: Still from Shorn – Allycia in foreground, dancing](image)

Allycia appears in the final cut of both *Shorn* and *18q-: A Different Kind of Normal*, and her dancing features extensively in the documentary. Showing her
love of dancing, her success and participation in the dancing world as well as the need to attend to her feet, which are misshapen and at times bring her discomfort, is really a metaphor for her life. We find ways to work through our challenges in a bid to realise those dreams and desires we wish to make manifest in our lives.

These markedly different experiences in crafting films within the black comedy genre, together with my engagement with fictional films during the past fifteen years, have to a significant degree shaped my belief that fictional film is a powerful vehicle for contesting the place of disability in today’s society, alongside the documentary form. Working in the realm of fiction paves the way for confronting issues that may be elusive to the documentary filmmaker in terms of access to persons subject to heightened levels of vulnerability due to intellectual impairment and inherent ethical concerns. So too, fiction provides a vehicle for a re-imagining of futures – hopeful or otherwise – which may prove more difficult to construct in the realm of documentary. I am hopeful that, in the future, I will be able to bring the two forms together in new and interesting ways to contest and represent ideologies surrounding disability. I have recently completed a feature-length screenplay treatment entitled *Tarnished*, which is a fictional interpretation of themes addressed in the film, and I will be developing this over the coming months.
The Autobiographical Choice

I have been commissioned to write an autobiography and I would be grateful to any of your readers who could tell me what I was doing between 1960 and 1974.

-Jeffrey Bernard

My choice to make an autobiographical work took some time for me to come to terms with, and was adopted towards the end of the first year of the project. I had no desire to be in front of the camera and had grappled with other ways of fashioning the work so that I could remain ‘out of sight’. I reluctantly agreed that this approach was potentially a far more powerful mode rather than a distanced critique of the condition, and what back then was looking like a talking heads film. I was, however, encouraged by the knowledge that while a work addressing Chromosome 18 was new, and there was still a paucity of autobiographical documentary films dealing specifically with disability as such, a rich library of fictional and non-fictional works addressing disability existed, as well as many autobiographical documentaries – many of which explore the experience of being ‘the other’.

The value of autobiography and its claims to truth and benefice for those born with disability and their communities is not necessarily a given, and has been contested in both the medical and the disability fields (Hardwig, 1997; Mitchell, 2000). These contestations are not confined to disability-focused autobiographies, with documentary theorists also challenging the value and worth of autobiographical films and their claims to truth. Hookham (2004)
examines the debate surrounding the representation of self as subject and the construction of truth in autobiographical works, presenting evidence that is both supportive and critical of the form. He devotes a substantial chapter to assertions of the form’s claims to truth, while conceding that the form is highly constructed – ‘a re-invention, a reconsideration of the past’ (2004: 44) and the capacity for distortion is encapsulated thus: ‘Our life is only tragic if we write it that way; we could just as easily reconstruct it comically.’ (2004: 44) He cites Carroll’s (1996) position that ‘different plot structures are implausible due to relations between cause and effect’ (2004: 44) in demonstrating the polarised opinions surrounding the autobiographical documentary. Adopting Bhaskar’s CR framework to challenge the polemics surrounding truth and authenticity of the form, Hookham concurs with Plantinga’s view that:

Films do not assert literal truth but rather they assert truth claims. For a defining characteristic of non-fiction discourse is that it makes direct assertions about the actual world, not that it makes true assertions. (1996: 132)

In rounding out the arguments for and against the challenge of both the literary and filmic construction inherent in autobiography, Hookham sees value in the form, having completed his autobiographical film in 2004. He concedes that these works only ever succeed in presenting partial versions of the truth – ‘a slice in the life of the subject portrayed, but this act, these works, nevertheless contribute to the acquisition of knowledge by critics, authors, readers and viewers’ (2004: 25).
I have also been keenly aware of Rabiger’s (1998) warning, alerting the filmmaker to the dangers intrinsic to autobiographical endeavour. He states that ‘little separates self-reflexivity from self-indulgence’ (1998: 335). I believe self-reflexivity has been an appropriate and potentially powerful strategy in bringing forth the beauty that exists within our lives. While it is my voice, and my story and Allycia’s, that primarily drive the narrative, the inclusion of multiple voices from our community as well as the joint storytelling that takes place, has ensured that the work has not degenerated into a self-indulgent piece offering a one-dimensional point of view. The slice of life – the moments and glimpses of our lives brought to the screen – offers viewers the opportunity to gain a sense of our experiences and hopefully, at some level, the chance to connect emotionally with certain aspects and characters featured in the work. However, if my expectations are not completely realised here, the film at the very least gives us voice and renders our community visible.

As the practice of crafting autobiographical documentaries has grown, a number of ‘sub-genres’ have begun to be categorised within the main genre. These include the essay, the diary or confessional, Renov’s domestic ethnographic film (in Gaines, 1999: 141), White’s historiophoty (1985: 193), autoethnography, the autobiographical/anthropological approach, and the call of Stys (2006) for visual narratives as teaching tools for Generation X and Y students studying bioethics. Stys cites a number of films, including the award winning Sound and Fury, as worthy examples of the ‘documentary bioethics genre’ (2006). 18q: A Different Kind of Normal may well be categorised as any or all of these, with the inclusion of the domestic space and relationships as a
vehicle for exploring the experiences of a group of people living with a rare medical condition, with the subjects commenting on issues of significant bioethical import.

However the film may be categorised or named, the autobiographical turn further complicated the project within an academic environment, with the associated ethical considerations intrinsic to an educational institution. The participation of the Chromosome 18 community – a vulnerable and at-risk community in terms of their disability status – and my personal relationships with my family, my children in particular, meant ensuring I developed a greater understanding of the potential implications of the work for those relationships. I was accountable to a university-appointed ethics committee governed by national guidelines designed to ensure a level of protection for people living with a disability. I pondered upon how the production potentially could result in negative outcomes for those in the Chromosome 18 community, how the work might compromise my relationships with my family and our community, and how I might best resolve some of the potential risks I identified.

I began attempting to ‘imagine’ how we might be ‘seen’ – was there the potential for issues to be misconstrued? Could I unknowingly be placing the subjects of the film under public scrutiny, thus making them subject to ridicule and judgement? Would my children be subjected to ridicule, and how would the intrusion of the camera affect them? And how would I negotiate with my family and the Chromosome 18 community should difficulties arise? The consensus from those involved seemed to be the only plausible way to
safeguard against the potential pitfalls. My life would continue outside the film, and I value my personal relationships with those in the film far more than the film itself.

The strategy I employed was to show progressive cuts of the film to our community and my family members – specifically those who feature in the film, including Allycia. I have on three occasions gathered feedback from each screening to our community to ensure I was reflecting experiences that were accessible, informative and respectful. In the commercial realm, this is not intrinsic to documentary filmmaking *per se*, but my personal feeling – particularly when dealing with persons whose view of the world is somewhat different to the average and whose understanding of the implications of submitting oneself to the camera’s gaze may not be complete – is that this is a necessary process. Issues of representation are made more complex by power differentials between filmmaker and subject, and it was to the significant, although somewhat unacknowledged, contribution of Edward Pincus to the field of the autobiographical documentary, with particular reference to his approach and the strategies he used when screening of one of his works, *Panola* (1965), that I turned.

Ed Pincus was a name unfamiliar to me prior to beginning this doctorate; however, his contemporaries – including Frederick Wiseman and Robert Leacock – were not. Interestingly, two of his students’ films, Ross McElwee’s *Sherman’s March* (1994) and Steven Ascher’s *Troublesome Creek* (1995), were among the many I viewed during my research (Lane, 1997). Pincus’s
influential work came to something of a halt in 1981 following his three hour and twenty minute autobiographical Diaries, resuming in 2007 when he, together with Lucia Small, brought Axe in the Attic to the screen.

Of particular interest to me was Pincus’s ethical approach, discussed by Lane (1997) in reference to his documentary work Panola, the film completed prior to Diaries. Pincus would not allow a screening of Panola without being present to ensure that the intent of the work could be clarified. His concern was that Panola, the gentleman featured in the film, would be depicted as ‘the tragic other’ due to the way in which he was captured on film. This desire – which appeared to me to be a protection of sorts of both the character portrayed and the way in which the filmmaker captured the film – resonates with the anxiety I have experienced in showing my film. I have been committed to working against the entrenched practices of representation and, understandably, have a keen sense of protecting those who have entrusted me with their stories. This has impacted significantly on the editing choices I have made during post-production, with the final cut crafted with a greater regard for protection of the film’s subjects. In the end-product, that may have diminished the potency of some of the storylines (for example, my relationship with my father) but this has been weighed against the wider implications outside the film.

In terms of the most important aspect of documentary work – access – we were the most accessible participants for the project and autobiography made sense. The decision to create the work myself, rather than enlist another director or seek broadcasting and government film funding, was driven by the
desire to retain greater control over the work and not be subject to another’s vision for the story, or the time, production and duration constraints imposed by funding providers and broadcasters. I have much to say about my daughter and the lives of people born with genetic difference, as well as the diversity and richness they have brought to my life, so constraining my voice, culling the footage and choosing the most pertinent themes and issues to address have all been challenging.

**Containing Content**

*You can't know too much, but you can say too much.*

*– Calvin Coolidge*

Capturing glimpses of one’s own life and that of one’s family with the view to sharing them publicly is not a project for the faint-hearted, and saying that it has been a challenging process is indeed an understatement. The project has faced many difficulties along the way, not the least of which has been my desire for the film to serve too many purposes with too many masters. It has been difficult to maintain clarity of purpose in terms of choosing the primary aims of the work as I have juggled the drive to educate and entertain with honesty, within a (sometimes murky) ethical framework. As I worked towards delivering the final cut and bringing the aims, subjects and subject-matter together coherently, shaped by a gentle, engaging aesthetic, I continually returned to the one underlying premise that had been my guide: the film was ultimately intended as a gift for Allycia.
My initial endeavour was, in retrospect, naively utopian. Although I knew intellectually that one film would not solve the world’s woes as I saw them, I wanted to take on all the issues I believed needed discussion and resolution and somehow cram them into one piece – to me, everything was important. So began the work of deciding whose voices would be privileged and which issues were, in my mind, most urgent. My desires for the film included:

- introducing an underreported genetic condition
- giving voice to those born with Chromosome 18 and their families
- a sense of a journey of discovery, moving from a feeling of isolation to a sense of belonging
- showing how we make sense of our lives with the ‘working out’ of our circumstances and a sense of purpose being born from those circumstances
- showing a realistic portrayal of life with disability in Western society today
- showing Allycia’s engagement in her life and her accomplishments, set against the limitations and expectations placed upon her
- exploring education and notions of inclusion for school-age children living with disability
- showing best practice in terms of medical practice and that, although medicine is part of our lives, it is not all of our lives
• offering other versions, alternate narratives and new stories about what a normal life might be like – and indeed challenging perceptions of normal, and by inference, worth

• provocation of the issue of pre-natal testing, how information is delivered and on what basis decisions regarding termination are made

• placing the history of disability against current attitudes about disability

• placing science, religion and image-making at the centre of the construction of disability

• exploring the economic consequences for families living with disabilities.

This list is a sizeable one, and presenting these issues within a coherent narrative has posed considerable difficulties in terms of structure and maintaining an engaging storyline. In addressing these issues, my intent was to construct a relaxed conversation with an audience, an invitation to accompany me on a journey of discovery and lay bare some of those transformative moments that have shaped my perceptions and affected our circumstances since Allycia’s birth. I was keen for a (my) subjective perspective to serve as a device for positioning myself somewhere between an audience and my daughter. In the beginning, I am ‘an outsider’ to the experience of living with a disability, and so am aligned with an audience unfamiliar with Chromosome 18. However, I maintain an intimate connection and identification with my daughter which demands that I take this journey and find out what it is she needs, and I succeed in a personal discovery of what it is I might need – a sense of purpose and community, and a need for self expression that is uncovered during the course of making the film. In essence,
I hope my audience will ‘discover’ people living with disability who continue, for the most part, to remain removed from society at large and that those who choose to embrace the film may discover something about themselves.

These aims are aligned with what Deetz and Simpson (2004: 45) describe as the ‘productive potential of dialogue’, raised in their discussion of ‘otherness’ and the formation of experience in that:

Only through our encounter with radical difference does transformation become[s]sic possible, as the taken-for- granted assumptions of dominant ideologies are made visible through juxtaposition with alternative understandings. If we encounter the other in this way, we not only challenge the status quo of existing systems, but also open the door to deeper self-awareness. Otherness may be present either in the concrete person standing there or in the way his or her understanding reopens the things of our world to redetermination. (2004: 145)

Placing myself and my family at the centre was a device employed to work towards minimising the distance between ourselves and an ‘abled’ audience. What I wanted to learn was as much a part of what I wanted to say in gathering the material for the final piece. For the most part, I was keen to show the ordinary aspects of our life without downplaying the challenges. I believe that to have constructed a piece that glossed over the difficulties we have faced would have been untruthful and risked a loss of resonance with a ‘dis-abled’ audience in not disclosing the challenges we all face. In this respect, I have sought to present a balanced portrayal of the genetic condition. The conditions and implications of being born with Chromosome 18 are vastly diverse, hence
my decision to introduce a number of different families whose experiences, while similar in some respects, demonstrate some of the complexities within our community. In addition, I was keen to show elements of overcoming our individual circumstances and a need to manage the physical ailments and discomfort experience by those affected.

As I worked towards shaping this gift for Allycia, I returned to the following basic questions in an endeavour to maintain focus:

- What did I want to say?
- How did I want to say it?
- How did I want a viewer to feel after viewing it?
- What needed to be said and shown to enable an audience to gain something – anything – from the film?

Underlying the aforementioned aims was a desire to say that my daughter and those born like her are valuable; however, articulating that idea is not as easy as it may seem. How can any parent articulate why and how their children are important to them, and surely this varies from parent to parent? The aim seemed futile at times, and often I wondered why was I trying to say anything at all – after all, it really is all just a matter of opinion. However, the disregard we had experienced in terms of a lack of respect and understanding in the public health system, and with our engagements with service providers, had so angered me over the years that I kept returning to a kind of ‘greater good’ perspective as a reason for completing the work.
My anger and frustration were great allies in terms of keeping me going; however, in choosing content and shaping a piece that might invoke connection and transformation for a viewer, I found anger was not a particularly helpful device. I have been described as relentless and unreasonable when confronted with issues concerning my family’s welfare. I can be extremely aggressive and dismissive of people whose attitudes, in my opinion, demonstrate ignorance about, and disregard towards, people with disability. When I get on my soapbox about the injustices to which people are subject due to inappropriate policy and care, I am not interested in conversation – I unleash. I do not believe that these qualities are particularly endearing, nor is my communication style particularly warm or inviting at these times. It has been enlightening to see how these strong emotions have found their way into previous cuts of the film, which subsequently have been revised. Ultimately, I really would like an audience to feel inspired by the people they meet in the film and hope that perhaps, as the credits roll, some of their ideas about what disability is and living with disability may have been challenged.

My guide and blueprint to fashioning an encounter with the difference that Chromosome 18 presents began with Bernard:
A story begins as a hypothesis or a series of questions and is refined and shaped every step of the way from idea to screen, until it has a compelling beginning, an unexpected middle, a satisfying end, and the kind of twists and turns that will get people talking. (2004: 2)

Easily read, not so easily manifested – particularly when framed within one’s own life, which is mostly mundane. I hardly viewed my life as compelling, although I had experienced quite a number of unexpected twists and turns, and my film wasn’t really about delivering a satisfactory end – our lives are always still a work in progress. What I did find compelling, though, was the opportunity to meet other people born with the same condition as Allycia, and to see how they had navigated their way through life. Clearly the work was going to be difficult to construct, particularly as much of the material was to involve personal interview and there was a definite danger of creating a piece that resembled a radio broadcast with pictures, rather than a documentary film. With this risk in mind, I turned to Ken Burns (in Cunningham, 2005) and his approach to storytelling and technique as inspiration, given his successful treatment of a number of subject areas including his most successful work, The Civil War (1990). Burns’ ability to turn a history lesson imbued with the politics of racial denigration, among the myriad issues war brings to the fore, into a highly acclaimed and much-viewed documentary series demonstrated an approach that I have attempted to emulate with the communication of complex scientific information concerning genetic conditions in a way that simplifies the text for an audience unfamiliar with the scientific and medical terrain. So too, rather than taking a moralistic or overtly politicised stance regarding issues such as pre-natal testing, inadequate care, special education and economic
inequality, I have delivered personal stories with the aim of connecting emotionally with an audience as viewers meet those whose stories tell of how we have dealt collectively with our own circumstances, and the ways in which we have created and re-created meaning in our lives.

I encountered a number of obstacles when it came to placing our community overtly within a political and historic context. For example, after having determined that I would use footage from the concentrations camps of Nazi Germany in a bid to place the discussion of pre-natal testing in a wider context, I purchased the rights to use selected footage to include in the film from the Steven Spielberg Film and Video Archive.

Two significant, separate events succeeded in bringing about my decision to discard the footage in the final cut. The first occurred in 2008, when a work associate and fellow filmmaker, Vickie Gest, presented a trailer at MIPCOM to garner interest from potential broadcasters. The feedback was not necessarily negative; however, one potential broadcaster, Global Telemedia, delivered the following communication via email:

Regarding 18q, we feel as if this special may be difficult as well due to the sensitive ‘value of life’ message – an important one I believe in, but still, nevertheless, controversial. (2008)

The second and definitive event was the distress the inclusion of the footage caused Allycia – I had to make the call, by inference, that it may equally distress her peers. While she has no knowledge of Nazi Germany, she found
the images of young children with numbers tattooed upon their forearms disturbing, and asked that the monitor be turned off. I felt I needed to respect her feelings about this sequence in particular. In retrospect, including the footage would have changed the tone of the film markedly, and would not have served the documentary as it is now structured.

On a number of occasions, I experimented with including other sequences featuring learned academics outlining the history of disability and others exploring religion as it pertains to notions of disability and sin; however, these explanations and asides shifted the work from the personal to the objective, with those expert speakers ‘feeling’ like they sat outside the story. In accordance with Burns’ tenet that ‘it’s not so much what you say yes to, but what you say no to in the business of film; the negative space of creation’ (in Cunningham, 2005: 18), decisions about what I excluded and why became as equally as important as the footage I chose to retain.

Following on from this commitment, much of the interview material filmed during the first two years of the project was discarded, due to the subjects or characters remaining ‘outside’ the world of Chromosome 18. The content of the interviews did, however, became part of the framework for the film. For example, the interview with Jani Klotz – whose story was the impetus for making this film – which was shot while attending the Chromosome 18 conference in Sydney, does not feature in the film. Her story was compelling and informative; however, two major issues succeeded in the interview being discarded – she is not connected to our specific community for the purposes of
this film, and her hesitancy (understandable) in exposing her family members and their stories on camera meant I had only her face and her voice relating the her story and those of her siblings. In person and on radio, Jani has tremendous presence, but without being able to access vision of her siblings, the story lacked the potency and connection I felt was needed to include it in the film.

The personal interviews remaining in the final cut are for me the strongest element of the work. I am fascinated by people and their stories, and none so strongly as the stories featured in this documentary. I find the families and those born with Chromosome 18 intriguing, and have gained much from the opportunity to meet and share time with them. The challenge was to find those moments, those phrases, those pearls that carried the most impact in communicating some of what I wanted to show. Sourcing adequate footage of most of the interview subjects was difficult, due to time, distance and financial constraints. The interviews obtained at the international conference, for example, were shot on the run, in between sessions with inadequate lighting and sound equipment (I left the microphones in New York), with Allycia by my side. These experiences are not unique, as I have come to understand, but were nevertheless difficult.

Obtaining observational-style footage of myself and my family together was difficult too, as we were all keenly aware of the camera and my son Adam, as shown in the film, has a particular distaste for being on screen. In reality, too, our lives are very ordinary and hardly filled with daily twists and turns that are
Filmworthy. However, we did manage to capture a few moments that show some of our family dynamics and the way the children interact with one another.

It was important to me that the content reflected the joy and humour we experience in our lives, and I was quite comfortable with having the camera capture my faux pas, as one of the aims of the work was to usurp the hero-making of the able-bodied carer that is so prevalent in disability narratives. I cannot recall the exact reason why I decided to hand the camera to Allycia when we lost our way to the conference in Plymouth, but the clip does bring humour and demonstrates the fun Allycia has brought into my life. These moments also facilitated variation in the pace and rhythm of the piece.

Another of these fortuitous coincidences that found its way into the film was when we had to leave our family home and my two older children moved to other accommodation. This, as is evidenced in the film, was an extremely difficult time for me, and while it is not obvious in the footage that appears in the final cut, I was extremely angry that my life had taken this turn. The day that I asked close friend and film director Martha Goddard to shoot us moving out of our home did not go quite as planned. In the editing suite, we have come to affectionately call this sequence, 'V's meltdown'. The inclusion is key for a number of reasons: it demonstrates my frailty unashamedly; the physical and economic challenges that face a single-parent family become apparent; and my role as carer is overturned as Allycia becomes both carer and muse here.
She brings a smile to my face in the midst of what was an extremely distressing time in our lives.

Far beyond the function of the piece in the film, this unravelling in front of the camera, and having to watch it back many, many times as we made decisions about what should be included and how we should cut the piece, has been an enriching experience in terms of documentary practice. This was an extremely confronting time for me in terms of viewing myself as subject and character within the work, and has served to further enlighten my perspective, sensitivity and communication with those who may in the future become the subjects of further work.

On a personal level, it has been interesting to view this ‘character’ on screen and see her from the perspective of a future that was unimaginable at the time of filming and has served to enhance my relationship with myself. The day of filming may be seen, from my own point of view, as one of the many ‘advantages’ of recording life as it happens.

The piece has taken many forms, and reflecting back upon the various treatments I have explored in the editing suite with the editors, what has become apparent is how strongly my emotions at the various junctures of my life are reflected in the content, and consequently the discarding of content along the way.
Having established what I wanted to say and what my ideal message to an audience might be, the work within documentary practice frameworks demanded a level of mastery embracing Cavalcanti’s ‘three inter-related spheres: the technical, the poetic, and the social’ (in Breitrose, 2002: 45–55). In terms of the social, my work had promise; however, the poetic and the technical presented greater challenges.

In essence, I had something I wanted to say: I love my daughter, she is different, yes it is difficult sometimes, but we also enjoy our lives, celebrate much and were changed by her arrival in ways that defy articulation. What I found was that I in fact had too much to say, which was the first and continued to be the last hurdle I finally had to overcome. My life had become vastly more complex and yet simpler in comparison to life before Allycia. Simplicity was found in the clear and present needs my daughter had. The value of life – her life – and as a consequence my own and my other children’s lives, became crystallised. I had begun to more fully realise the frailty and precarious nature of ‘living’ and ‘being’, and how precious ‘life’ is. The value of ‘living in the moment’ became clear – it really is all we have.

The complexity arose from within – my own ideas about life with physical and intellectual impairment were challenged, as were my reactions and my expectations about my daughter. Further complexity arose with the attitudes that confronted me in my daily dealings with health-care professionals and service providers. There was a distinct lack of understanding regarding our lives and our needs. The condition with which Allycia was born is still largely a
mystery, and we as a society have not yet found a way to embrace persons of difference in their fullness. As I began to reach out and learn more about living with disability, I found that my own experience was not unique. Prejudice, lack of understanding and knowledge, inadequate support, disrespect and ignorance were the warp and the weft of our lives. I have struggled during these past five years in choosing the most important aspects of our experiences to share in the film. Many themes are alluded to in the film, as I have endeavoured to weave the complexity of our experiences into the work.

I faced significant challenges in creating the narration as I considered, as directed by my supervisor, ‘issues of character development, psychology, suspense and rhythm as inescapably as those of accuracy, persuasion and advocacy’ (Laughren, 2008) as the framework for the work. I have endeavoured to capture and contextualise our family’s experiences as essentially ordinary, with moments of triumph and heartache. On paper, this may not sound like a particularly inviting proposition and rather lack-lustre in terms of character development or suspense. However, in terms of a place within the disability literature, I am endeavouring to subvert the stereotypical characterisations associated with disability, including hero-making, the tragic and pitiable other, and the isolated other by re-presenting a rare medical condition within the context of everyday living.
A Question of Character

"Character is like a tree and reputation like a shadow. The shadow is what we think of it; the tree is the real thing."

- Abraham Lincoln

Within documentary, as in fictional film, many spaces and variations for characterisation exist. For some works, the environment may be at the heart of a story; for others, a cause or a social phenomenon can pose a threat of some kind. Then there are those stories that are heavily character driven – they focus on characters we wish to see succeed or fail in their quest, depending on how we evaluate their motivations or how we and judge them as they are portrayed in the works (Bernard, 2007: 21–4). A Different Kind of Normal is not so easy to characterise within these treatments, so the intent of the film may well be misjudged, depending on the viewer. However, from my own perspective, while the piece does sit within the dramatic genre, the characters – the people I met during the course of making the film – were compelling. I desperately wanted – needed – their stories, not for the film but for myself. I was looking for answers, for hope and for connection, and in my quest I found a measure of success and satisfaction. For me, delivering the story of this journey meant delivering the compelling tales and personalities of the individuals who made a significant impact upon the way I view disability today. (There are many, many other people I met during the course of filming whose stories as yet remain unseen.)
During the course of conducting interviews, Allyinga and I met many families and individuals, and from my point of view they were all worthy of screen time. Unfortunately, however, this is not the nature of filmmaking, and I would hazard a guess that not everyone would find the material as interesting as I did. So began the problem of choosing who would stay and who had to go. While at the outset I had a clear purpose in making the film, the content was as much an adventure into the unknown as the journey experienced by any other researcher. I did not know who I would meet, nor did I realise how they would change me. Apart from those living with disability, we met other characters who existed somewhat ‘outside’ the story of 18q-: A Different Kind of Normal. Some have remained in the film, while others – whose knowledge, wisdom and sharing nevertheless have enhanced the story – now remain only as saved files on a computer disk. To those people, I can only express my sincere thanks and gratitude within these pages.

As 18q-: A Different Kind of Normal is an autobiographical work, an audience might rightly assume the film is about my journey with Allyinga; however, as the autobiographical turn was employed as the central storytelling device rather than as the imperative to make the film, exploration of my character per se is not at the heart of this film. I certainly believe an audience will gain some insight into how my ideas about living with disability have changed, and see that what I once viewed as a hopeless future has to a great degree been changed to one that is more hopeful. To construct one’s own character on film is quite a task – one that is most disconcerting and certainly revelatory when faced with having to watch oneself hour after hour in an editing suite. This
experience has changed markedly both how I view my craft and the way I view myself. To view that person at a different time in a different place has been a surreal experience, and has taught me to see myself with greater compassion. It is a lesson that I believe will serve me well in my future documentary endeavours.

Which Veronica was going to be privileged in the piece was key. I believe that to have given over fully to the anger and frustration I felt in the early stages of filming would have resulted in a far more self-indulgent piece, and may also have served to distance an audience from the work. Certainly some of my more animated, vitriolic soliloquies could have made for interesting viewing; however, laden as they were with judgements and vehemence, they could either have served to make an audience cringe or might have risked dissolving into comedy – at least according to my children, who have at times been on the wrong end of one of my rants. So it is a very restrained Veronica who is present on screen, and certainly those who have worked with me and those who know me well would agree. I believe she has served this film in a more positive way in terms of enlisting an audience to take the journey with her, and to witness my endeavour to impart some knowledge of the condition and our collective experiences.

Within this restrained Veronica, many Veronicas exist:

- Veronica the activist – who desperately desires change in attitudes towards, and institutions for, those living with disability
• Veronica the citizen – who believes medicine, technology, law, ethics and politics take on renewed significance when living with genetic disability
• Veronica the filmmaker – wanting to do the subjects, the medium and the content justice and create a piece that someone will watch
• Veronica the researcher – exploring the medical and social consequences of being born with genetic difference, and giving voice to issues surrounding living with a disability in an arena where changes can be made
• Veronica the mother – fiercely protective of my daughter, my family and others ‘like’ us
• Veronica the woman – who flounders, grieves, makes mistakes, dreams and celebrates.

These character traits emerge in the film with varying degrees of exposure, and I believe some are present to a lesser degree than others – implicitly rather than explicitly. For example, the content included in the film and the subject-matter conveyed in the various interviews reveal answers to my unheard (off-screen) questions. So what I have omitted also could be said to reveal my character. My position as Allycia’s mother, and as part of our community, has certainly limited what I have chosen to include in the final film. Some of Allycia’s more interesting ‘ways’ and her more difficult days have not been the focus of the film. In my endeavour to posit an alternate narrative to the entrenched portrayals of disability, I have included some of the challenges we face as families and as individuals, but my aim has been to include them as
part of life’s everyday events, which simply need attention and require strategies to navigate our way through whichever challenge may present itself at any given time.

As part of this endeavour, my intent was to show how we as parents confront our own issues, and how we resolve and work through the physical and medical challenges that become part of our experience. In the stories presented to us about disability – and indeed, within the context of our own lives – there is often a perception that a kind of heroism is coupled with the challenge of parenting a child with disability. I was keen to dispel some of these sorts of narratives, having been on the receiving end of phrases such as ‘only special people are given special children’. While on one hand this kind of ‘compliment’ is intended to be positive and encouraging, I have often felt that while on the one hand it inferred that I was a special person, at the same time it gave others an excuse for not engaging. I was keen to portray us as parents as ordinary, flawed people who simply love our children and have to find ways to resolve those issues we encounter.

To this end, I examined the way in which Ross McElwee had approached characterisation of self in his works, specifically *Sherman’s March* (1986) and *Time Indefinite* (1993). I saw the inclusion of what Dovey (2002) describes as McElwee’s ‘anti-hero’ persona as a useful device in working against the ‘carer as hero’ constructions so often seen in disability narratives. Just as Rabiger (1998: 336) placed McElwee’s position in his films as one of ‘everyman’, I was keen to create a kind of ‘everywoman’ persona for myself. It was somewhat
fortuitous then that those moments of my being lost were captured on film, particularly when Allycia and I got lost on our way to the international conference, and Allycia attempted to capture my image on camera. In the sequence when we are leaving our family home, my frailty and failure to keep my family together are captured. Allycia succeeds in turning my attention from my grief, and in fact becomes ‘the carer’, offering me a torn tissue for my tears.

I believe one sequence in particular demonstrates much of the underlying ‘message’ regarding individuals born with genetic difference. It involves Susan Baldwin Shafer. There is omission here as well as revelation, whereby I do not delve into past events surrounding the birth of her daughter; however, we find out how much Susan misses her daughter, indicating that they do not live together. Susan speaks of her physical condition in medicalised terms and presents as a confident public speaker addressing her peers. We see her stand against the loneliness involved in being ‘othered’; we see her cry and grieve, and we see her embraced by her peers at this low point. Susan’s story – her character – brings much to the film by way of challenging ideas about disability. She is married to Paul, an able-bodied academic whose view that ‘nobody’s perfect’ is brought to the film. Most important of all, within the greater project for me outside the work of this film, is the fact that Susan’s genetic difference was not detected until she became a mother – she had escaped the gaze of the microscope and her life marks the defiance in many respects of the prognosis delivered within the confines of medicalised categorisation of genetic difference. Each person brought into the world of this film offers a different
facet of the mystery of our genes and defies the notion that their lives are not worthy of ‘being’.

While I feel free to espouse these strong opinions on paper, I fear the finished film will appear to shy away from further exploring many issues raised in the film; my personal dilemma was with my deep connection, affection and respect for the people with whom I was intimately involved. They exist outside the film in a very real way for me, and they are much more than characters on a screen. Some of my relationships with those on screen existed before the making of the film, and certainly those relationships have continued since completion. Hence the way in which each person is portrayed matters to me within the life I am leading beyond the film.

My belief, based as much upon my own engagement with film texts as on theoretical frameworks, was that for an audience to engage with the film they would need to feel a degree of affection for and empathy with Allycia. The Allycia I endeavoured to show on screen was the very best of Allycia, but I also felt compelled to show that she is not without challenging behaviours, just as her siblings have exhibited challenging behaviours as they have grown. I wanted to capture some of the family dynamics, but this proved extremely difficult given my son’s discomfort with the camera’s presence in our lives. For this reason, the footage of our family breakfast barbecue has been included. Feedback from the first screening indicated that not showing some of Adam on screen left questions in the audience’s mind about his role and place in the family. This scene also demonstrates the usual conflicts that siblings
experience, including Allicia’s sometimes precocious behaviour and the fact that my older daughter Kristina is not always happy about how things are done.

How Allicia engages with and experiences medical treatment was critical in showing the discomfort she experiences, how she deals with her challenges and how, in Dr Peter Smith’s case, best medical practice can enhance the experience of ongoing medical treatment. Peter is one of the few characters included in the film to sit ‘outside’ the Chromosome 18 experience in terms of physical and familial connection; however, he and photographer Rick Guidotti, in spite of not being directly affected by the condition or related to the community, are very much a part of the community by choice. Although it is not made explicit in the film, Peter has conducted ongoing medical research with people born with Chromosome 18 anomalies for a number of years in Australia, and has a keen interest in the area. Rick Guidotti has become a ‘regular’ at each United States-based Chromosome 18 conference, and is well known and regarded within the community and many other disability organisations in the United States. He brings a freshness and honesty to the experience of meeting persons of difference as he tells his story in the film.

His position as an ‘outsider’ who has found ‘their way in’ is one that I hope gives a wider audience access to our world. His delivery of ‘what the heck is a chromosome, I’m a shallow fashion photographer’ was a serendipitous moment captured on camera as he lays his ignorance of the existence of the condition before an audience and goes on to explain his own moments of transformation. With his admission that he is shallow, and that through his eyes
people of difference are beautiful, but ‘we’re just trained not to see it’, he throws out the challenge to all to examine our own culturally defined norms of what beauty has come to mean in Western society today. Displaying his portraiture of our children and adults, and the moments he has captured on film, defy those that populate the pages of medical journals. Those images that treat the human subject as an object of fascination from a static viewpoint are a far cry from the vibrant, articulate young people we meet in the film.

Figure 4.8: Still, Allycia and Rick Guidotti, Sydney

Each family and interviewee has been chosen to offer perspectives that challenge those medicalised and dehumanised images as they reflect upon their own experiences, their learning and their transformations in navigating their way with the prognosis of Chromosome 18 difference. As there are in excess of ten interviews, included in the film, apart from my family’s, I will confine further discussion to the stories of one interviewee from Australia and
two families from the US conference that were particularly powerful from my perspective.

John Kiely, the grandfather of Tameka, gives an honest account of his granddaughter’s short and painful life. Including this story may in some respects seem to be contradictory to the overall intent of this work; however, Chromosome 18 anomalies are as diverse in their configuration as the physical manifestation of those anomalies in the people born with them. Tameka’s experience and subsequent death highlight the failure of medicine to cure her or bring her any measure of comfort – she remains a medical mystery. To not include at least one story illustrative of the extreme conditions that this disorder can manifest would, I believe, leave part of the story untold. Tameka’s story also raises issues of medical and moral ethics in terms of the issuing of ‘no resuscitation’ orders and the failure of social services and infrastructure that led to her placement in an aged care facility. While John acknowledges that this was the best available place for Tameka, and that the residents gained a great deal from her presence, the fact that this was the only suitable facility for a young child with chronic health ailments raises the issue of how to best care for and support young people with disability in these situations.
At the conclusion of John’s interview, I broke down and asked that the camera be turned off. His family’s experience touched me deeply with the hopelessness of their situation, and the discussion of Tameka’s suffering delivered me back to those first months of Allicia’s life when she was subjected to many painful procedures when she experienced cardiac failure. I had a number of moments that brought me undone as I spoke with and listened to others’ stories. I cannot really evaluate these experiences as positive – while it is important to share our stories for those who are beginning their lives with Chromosome 18 differences, for me it is equally important that we continue to move forward and not dwell upon those sometimes painful moments in our past. Images of Allicia’s small, frail body being assaulted with many needles and her tiny face filled with pain, following open-heart surgery, whenever she sneezed or tried to laugh are deeply embedded in my memory.
and stories such as Tameka’s seem to transport me back to that time, accompanied by the trauma and painful memories associated with it.

Likewise, Scott and Irene’s story brought many painful memories to the surface as they shared their experiences with their children – Caitlan, Brianne and Steven – on camera. Their story brought up many issues with which I had grappled as they openly discussed their experiences with pre-natal technologies, reshaping their ideas about themselves and the future of their family. The moment when Irene’s mother reveals she is the carrier of the gene that her two grandchildren have inherited and talks about how she has come to terms with this new-found knowledge is also painful.

Figure 14.10: The Lammers Family at the Plymouth conference
Kathryn and Martin’s story is the highlight of the film for me, as their openness and spontaneity are captured on camera when they share memories of how they met and in unison tell us it ‘was love at first sight’. The manner in which their parents speak of their children’s romance and how this has impacted upon them is empowering. I realised during this interview that their story raised many questions for me about how I would navigate my way with Allycia when confronted with her relationships in the future. As she was only twelve at the time, I had not thought that far ahead. Hearing Kathryn and Martin’s story gave me confidence and hope for the future, and the ability to see the possibilities awaiting Allycia.

Engagement with my family, our community and myself through the process of crafting this film has heightened my awareness of the power relations inherent in the privilege of making a documentary film. These power relations are magnified exponentially when dealing with people with intellectual difference. This is not to say that the adults living with Chromosome 18 difference I interviewed necessarily have diminished intelligence – Kathryn, for example, has completed her Masters in Science. The power differential here can best be explained by an editing choice I made in the final cut. The previous cut had included Kathryn and Martin exchanging a kiss in front of the camera, with Allycia off camera. As they kissed, I panned the camera across to Allycia to capture her reaction. It was an impulsive movement driven by her reaction – quite a typical reaction of someone her age to a kiss – gross! This was for me a precious moment of sharing with just the four of us in the room. However, I felt increasingly uncomfortable about the scene as I began to think how my two
older children might react in the same situation. Would they have felt as comfortable kissing their partners in front of the camera? Would they have consented to having the moment screened? Kathryn and Martin were entirely comfortable with the show of affection for one another, but in the end I discarded the footage. For me, this scene felt voyeuristic and intrusive, and was not necessary in the context of this film.

This experience has shown me the potential risk as a filmmaker when dealing with people of intellectual difference. While it is a highly contested stereotypical statement in terms of disability scholarship, my experience is that our children – whether they be child or adult – are in general very trusting people: they do not, in my experience, have the capacity to evaluate their safety at times, particularly in social situations. I believe these are extremely difficult calls to make when dealing with people of intellectual difference, and for me – probably more as mother than as a filmmaker – upholding the dignity of those willing to share the stories of their lives on camera is crucial. This is difficult terrain, given notions of what dignity might mean to different people and the stories we wish to craft on film, but I have referred back constantly to how I would like to see my children portrayed, and endeavoured to deliver on what I feel brings dignity.

In terms of delivering myself as a character, dignity was not necessarily at the core of the way my final character was portrayed. I believe there are aspects of the flawed anti-hero in the film – and it is disturbing to realise they emerged without me even trying. However, the sequence of my breaking down as my
older children moved to different homes has given me far greater insight into how fragile we, as human beings, can become when under stress, and how unexpectedly ‘cracks’ can appear. In terms of documentary filmmaking, this is what we are looking for; however, I will not know now until I have the opportunity to turn the camera on another how this experience has affected my practice. On the one hand, I believe the experience has given me greater confidence to allow events to unfold before the camera; however, after experiencing much discomfort for many months when revisiting these images, I am not so sure that I feel so confident in encouraging others to bare it all. In spite of being able to overcome my personal discomfort with the sequence (save Allycia’s moments on screen), and the belief that the sequence brought some critical issues surrounding living with disability to light, I would rather not have gone through this particular part of the process.

My experience in this process has underlined Ruby’s assertion that:

> Questions of narcissism, of turning oneself into an object of contemplation, of becoming a character in your own ethnography are very fundamental and complex questions. (1980: 160)

I believe these experiences have provided a basis for furthering Ruby’s argument that what ‘anthropology has to offer is primarily a systematic way of understanding humanity-our own as well as everyone else’s’ (1980: 161). The camera is a powerful and wonderful tool, one that has given me licence to conduct intimate conversations with people I barely knew – they would become ‘characters’ in a film but would also become companions and friends outside the film. These relative strangers, with whom I feel very strong bonds, have
entrusted me with the telling of the joy and the sorrow of their lives, believing I would do justice to their trust. I have endeavoured to deliver on that trust.
5

Ethics: Towards an Understanding

Counter-stories then are stories designed to repair the damage inflicted on identities by abusive power systems. They are purposive acts of moral definition developed on one’s own behalf or on behalf of others. They set out to resist, to varying degrees, the stories that identify certain groups of people as targets of ill treatment. Their aim is to reidentify such people as competent members of the moral community and in doing so enable their moral agency.

- Nelson (2001: xiii)

During the process of creating this work, it increasingly became clear to me that the questions asked and issues raised would deliver very few definitive answers. The work has given rise to many more questions, demanding further academic inquiry – particularly in the realm of ethics and documentary film practice, and the ethical treatment of persons with disability – the areas I have found to be most challenging and at times enlightening.

The scope of this work is not intended to be prescriptive in approach – there are many implications inherent in working with one’s own family and people of genetic difference. Each group of people – indeed, each individual – represents uncharted territory. Rather, the intent is to outline the veritable minefield that awaits those who wish to engage in such a project. The idea of telling one’s story seems to be such a simple one; however, as I discovered, it
is far more complex than I could have imagined. The challenges within the work undoubtedly arose partly due to the absence of any distinct ethical framework within documentary practice for crafting a work involving myself as filmmaker and subject. They also related to being so closely connected to a group of people categorised as disabled, and therefore as potentially vulnerable due to their intellectual status.

This absence of guidelines for ethical conduct within documentary filmmaking in the Australian context, discussed at length in Blackall (2004), which reveals the many contradictions and challenges inherent when crafting a documentary with a vulnerable subject, has meant a virtual building of a framework for my film from the ground up. In addressing the need for more widespread dialogue between documentarians and camera journalists, and relevant educational bodies, Blackall contends that ‘ethical discourse must have a place in world public debate and it must be applied in a pluralistic process where all involved have continuous dialogue and contribution’ (2004: 351). Using the events surrounding issues of informed consent arising from Dennis O’Rourke’s *Cunnamulla* (2000) as a case study, Blackall highlights power relation differentials in terms of the communication between filmmaker and subject, and an apparent lack of understanding on the part of the subjects as well as their failure to understand the potential implications for the recording of their intimate, private lives. The case highlights the risks inherent in documentary filmmaking as craft and profession, and more importantly, the risks to those we film. *Cunnamulla* demonstrates the dangers involved in working with potentially vulnerable subjects, and raises questions that also arise in working with
persons of varying intellectual capacities and those affected by psychiatric conditions that may affect an individual’s decision-making capacity at different times. The risks for people who may not fully understand the longer term ramifications of consenting to be involved in a documentary project can be grave; however, as Evans (2007) contends, there is also a danger of being overly prescriptive and judicious to the detriment of those whose stories need to be told.

Evans (2007: 45) cites the case of Michael Noonan’s controversial PhD documentary *Laughing at the ‘Disabled’* (later renamed *Laughing with the ‘Disabled’*) as highlighting ‘the sensitivity of some research and the potential for disagreement about what is a suitable way of protecting vulnerable subjects’ (2007: 5). The case brought into relief the polarised viewpoints that exist regarding how best to advocate for those of differing intellectual capacities. On the one hand, our project within disability is to escape the patriarchal confines that have entrapped people of difference; however, I feel that for those who are perhaps not fully able to comprehend the extent of risk to which they may be subject, safe passage must be provided in order for them to achieve autonomy in a world still lacking awareness and compassion with regard to persons living with intellectual or psychiatric disability. These are difficult questions that are not easily answered, and they require much further discussion across the many sectors involved in these processes.

These dilemmas are not confined to the Australian context. The American University’s School of Communication conducted a baseline research project in
2009 that involved 45 documentary filmmakers. It explored the ethical challenges inherent in their work, given the fact that a specific ethical standards regime for documentary practice has yet to be articulated in the United States (Aufderheide et al., 2009). The findings reveal the lack of coordinated communication that exists when it comes to facilitating industry-wide discussion, as well as a hesitancy from practitioners to disclose their practices, due in part to the demands and constraints within the commercial world of documentary filmmaking.

While I did not have a set of professional industry standard guidelines to inform my work, I was bound by my role as an academic by Australia’s national guidelines for research involving human subjects. These were overseen by the National Health and Medical Research Council (NHMRC, 2007) and the university’s Human Research Ethics Committee (HREC, 2011). To continue the work, I had to address the requirements of my then university, Queensland University of Technology, by submitting paperwork for ethical clearance at the highest level of clearance (Level 3) due to the nature of the community I was researching. Members of the Chromosome 18 community affected by the condition are categorised as having varying levels of disability, which identifies them as being more at risk than the general population. More specific guidelines have therefore been designed to protect their human rights and minimise exploitation (NHMRC, 2007: 51–76). The document uses language admonishing us to respect our human subjects and challenging us to weigh benefits versus risk for vulnerable communities (2009: 65–6). However, explicit directions are absent from the document – given the vast diversity of human
subjects, a manual for addressing each possible scenario hardly seems practical. In the absence of more concrete directions and suggestions that may have included evidence-based scenarios, I was required to furnish strategies that I felt would be appropriate to my particular project.

My close personal relationship with the community, together with the implications of working with my family and subjects who were under the age of consent, made the project more complex. My relationship with my family and community was potentially at stake, hence an outline of strategies for dealing with these risks to my subjects and to myself was submitted to the university’s Ethics Committee. In asking those closest to me to share their experiences, I was asking them to allow an unknown public to access their private lives which, as demonstrated by my son’s reluctance to be involved to any great degree in the work, is not for everyone. I provided letters of support from the Chromosome 18 Registry and Research Society and submitted the referral back to my community and family with progressive cuts of the work as the key strategy for ensuring the community was happy with the work, paving the way for open dialogue and opportunities for changes when and if required. Following the successful application to the committee, I was then allowed to continue the work.

Moving beyond the academic guidelines, my starting point within documentary film theory and practice scholarship was with Bill Nichols (1991, 2001) and Brian Winston (1995), both having devoted much work in examining ethics within the field. Nichols sees that ‘Ethics exist to govern the conduct of groups
regarding matters for which hard and fast rules, or laws, will not suffice.’ (2001: 9) and raises concerns surrounding the communication of the filmmaker’s intent to the subject and the ability of the subject to grasp the possible outcomes that may eventuate as a consequence of their participation. Winston (1995) points towards the myriad factors impacting upon the production of a documentary film, including the director’s own beliefs, the construction of the work and artistic considerations. He asserts that the autobiographical move has the capacity to challenge some of these distortions or act as an antidote to what he terms victim documentaries.

Gross and colleagues (1988), in their volume addressing the moral rights of subjects whose images are captured on film, television and camera, provided a stepping stone for building an ethical framework in terms of obligations and responsibilities intrinsic to documentary filmmaking:

1. The image maker’s commitment to him/herself to produce images which reflect his/her intention to the best of his/her ability.
2. the image maker’s responsibility to adhere to the standards of his/her profession and to fulfil his/her commitments to the institutions or individuals who have made the production economically possible.
3. the image maker’s obligation to his/her subjects; and
4. the image maker’s obligation to the audience. (1988: 6)

The first obligation appeared to be relatively straightforward: my commitment to raising awareness of the existence of a group of people living with a rare chromosome condition was unquestionable. However, delivering on that intention has been made complex due to my positions as subject, parent,
advocate, community member and filmmaker – which role was to be privileged over others became a matter of deep consideration as I progressed with the work. Which role demanded the greater responsibility was key – in the end, I believe it is the role of mother that has been privileged above the others, and it is the one I feel most compelled to consider.

The second obligation was primarily defined within the academic environment, and for me at the personal and professional levels I am bound philosophically to what I perceive to be the traditions of ethical documentary filmmaking. Therefore, while guidelines were not necessarily articulated in a prescriptive form, my research and experience as a filmmaker furnished the building blocks upon which to proceed.

With documentary film theory as the foundation of the framework I would eventually craft, I found Katz’s extensive chapter covering Ira Wohl’s films, *Best Boy* (1979) and *Best Man* (1997) (2003: 327–42) to be useful in charting my journey and delivering satisfactory adherence to the third obligation: to my subjects. Wohl’s films document the experiences of his cousin, Philly – a 52-year-old man in *Best Boy* – who lives with intellectual impairment. Katz’s discussion illuminates the tremendous power a filmmaker has in working in close familial proximity with one’s subjects, in particular a person living with intellectual impairment. Katz contends that while Wohl’s practice meets three of the four criteria in terms of a filmmaker’s obligations and responsibilities, he is not convinced that Wohl completely honours his obligations to his subjects, including Philly and his parents. Katz questions notions of informed consent.
and power differentials with regard to both Philly and his parents. If Philly was intellectually impaired, could he fully understand the endeavour to which he was consenting? If Philly’s parents were not related to Ira or had access to greater means of financial support, would they have consented to allowing their personal lives to be displayed in such a public manner?

It was within in this realm that I too was challenged when issues around my son’s image being used in the film became apparent. Although Adam was supportive of the film and believed in the value of the work, he was not comfortable with his private life being placed in the public sphere. My concern about his absence from the film was not unfounded when, following a screening of one of the earlier cuts, I was questioned about my son’s absence and it was suggested that this perhaps left space for certain assumptions to be made – for example, his absence from the work could intimate that he did not play a significant role in Allycia’s life.

Adam certainly has played a significant role in Allycia’s life, particularly given my single-parent status and the absence of Allycia’s father in her life. As Adam’s mother, I felt a compulsion to make sure an audience had some knowledge of Adam’s significant contribution in her life. As a filmmaker, it felt like a ‘gap’ existed that needed an answer. If was fortuitous, then, that on Mother’s Day 2006 he spoke to me of his feelings on camera. Adam and I discussed including the clip in the final piece, and while he did not share my concerns about the possibilities of misperceptions about his character, he did consent to my use of the footage. To reiterate Katz’s point regarding the
differing power relations that exist in a work of this kind, I need to concede that had anyone else apart from me asked for consent, it may well not have been given. I am still not entirely comfortable with my decisions, particularly as I believe my appeal for the ‘greater good of the Chromosome 18 community’ and the ‘greater good’ for the film underlaid our dialogue. Adam assures me he is happy with the way the film has now been finished, but I am very much aware that my choices could potentially put our relationship at risk.

Many subject areas are touched upon in the film, including the notion of the ‘medical gaze’ versus Guidotti’s challenge of seeing persons of difference differently – a direct challenge to the medical imagery and representation of persons whose genetic makeup is categorised as abnormal. Education of persons of differing intellect is addressed via interviews with Allycia’s teachers, who postulate that there is something of value for all in special education contexts. Best medical practice is brought forth as the viewer becomes privy to the interactions between Allycia and one of her specialist doctors. Notions of community and support are explored as I venture forth to find people like ‘us’ with whom to connect. Concepts of vulnerability due to economic circumstances brought about by the extra care my family requires are laid bare before the camera, and Allycia as ‘carer’ emerges as she comforts me in my distress and brings laughter and comfort to a challenging situation.

Assertions by people of difference saying ‘they love just like everyone else does’ signify their awareness of both their difference and similarity to ‘able-bodied’ others. The impact of religiosity is alluded to in the exchange between
my father and me as we discuss his judgement upon my situation and my anger towards him. Notions of those with intellectual impairment being unsafe outside the confines of their community also are alluded to as Elizabeth Cody’s sister Catherine speaks of the freedom Elizabeth has at a Chromosome 18 conference compared with her life at home and ‘out in the world’. The dilemma of familial relationships that are challenged when bringing the gaze of the camera into one’s own domestic space is articulated as my son challenges the intrusion of this work into our domestic space. The film explores parenting of children with genetic difference and the guilt associated with medical diagnosis – or ‘who is to blame’ when identifying which parent carries the defective gene. The potentiality of the unborn is brought forth as discussions around pre-natal testing emerge and I ponder the difference between knowing Allycia’s genetic makeup and the person she will ultimately become.

Bringing each of these issues to the screen has demanded ethical interrogation – and indeed the omission of some material was driven by a similar imperative. For what use or purpose would a particular interviewee or scenario be included or excluded from the final cut? What benefit could be derived by either exclusion or inclusion? How would I address each participant during the course of an interview? These are complex questions that in the end are filtered by questions of whether they stay or go, and how they serve the film or the people the film claims to represent. From the outset – from the initial academic application outlining strategies for the ethical treatment of human subjects required by my university for ethical clearance to begin the project – until the submission of the final work, questioning what ethical framework would
underpin the work has been central to my process. This chapter is devoted to a discussion – albeit brief within the vast scholarship devoted to ethics across the many disciplines the work crosses – of these ethical considerations.

As the project progressed, I learned of other risks I had not considered in terms of my responsibility towards my subjects and ensuring they could participate in a manner with which they could remain comfortable. How I asked questions was particularly pertinent, and I learned very early about how distressing this could be with an interview I conducted with a young man affected with Chromosome 18 difference. In my eagerness to properly articulate a question within what I perceived would be an understandable framework for him, I succeeded in overloading him with information. This resulted in the young man becoming flustered and being unable to answer me. He then felt inadequate, and I went to great lengths to assure him the fault lay with me and not him and apologised for my inadequacy. I became acutely aware of the ramifications of my actions upon those who chose to speak with me, and the knowledge that my actions had the potential to impact upon them in very real ways – beyond the world of the film. My desire was that the experience of telling their stories would serve to help them feel heard, not inadequate, so my approach became more measured and I endeavoured to watch and listen more closely for any sign of discomfort or distress.

The degree and the manner by which I delved into people’s private lives also put me at risk of overstepping boundaries and risking my ongoing relationships with those people outside the life of the project. I confronted this particular
challenge when I asked Kathryn and Martin’s parents about their thoughts regarding becoming grandparents. They unequivocally refused to answer this question on camera, but said should I need to discuss this question parent to parent they would be happy to do so. I chose not to include this exchange in the film – these are questions with which I grapple, and have no easy answer as I cast my eye towards an unknown future as Allycia grows into womanhood. At the time of filming, the couple’s relationship was still quite new and their parents were still coming to terms with Kathryn and Martin’s blossoming romance. The question from my perspective was asked from both a personal and professional point of view. Pondering the prospect of our children having children is, in my experience, a fairly common phenomenon. With the extra care and support that our affected children require, and the possibility that their children will have similar needs, discussion and exploration of how we would navigate our lives in the event of having grandchildren to care for as well is important and remains uncharted territory. I felt that Susan Baldwin Shaffer’s story of the birth of her daughter and Elizabeth Cody’s desire to have two children – one with Chromosome 18 difference and one without – gave space and time for pondering some of these questions, rather than showing Kathryn and Martin’s parents refusing to answer a question.

There is also a future risk wherein perhaps Allycia, when she reaches a certain age, may not be happy with how I have approached the work and with the way I have depicted her and her community. This is a future concern with which I may or may not have to contend; however, I feel the piece I have delivered is one that shows respect and dignity towards those who have chosen to be a
part of it, so feel at ease at this point in time that I have proceeded with the work with the intention that it be distributed as widely as possible.

Upon reflection, the impetus for this work was steeped in my interpretation of, and perceptions about, an ethics of the representation of ‘the other’ – although until beginning the work I would not have perhaps phrased the intent in this manner. At the time of embarking upon the work, my desire had been to produce a work that introduced my daughter Allycia and her community to what I perceived to be an unknowing public. Intrinsic to this desire was my experience as a parent of a person born with genetic difference, a situation in which I had been confronted with what I believed to be ignorance and misinformation surrounding her medical condition and her potentiality, and by inference her viability as a human being. During the years of crafting the work, I have come upon what I believe is a theoretical expression of what lies at the very heart of the project, echoed in the work of Kaya Silverman (1996) and her notion of ‘the possibility of productive vision’ and the capacity for ‘an eye capable of seeing something other than what is given to be seen, and over which the self does not hold absolute sway’ (1996: 227). She says to future filmmakers and photographers: ‘I utter only one short but passionate appeal to those now working in such areas: help us see differently.’ (1996: 227) It is my hope that 18q:: A Different Kind of Normal contributes to the project of seeing the ‘disabled other’ differently, and in so doing succeeds in honouring an audience that has the privilege of meeting the people in my film.
Framed in this way, the project is deeply concerned with ethics – the ethical treatment and representation of persons with disability. My experience had revealed a need – that of my community, and indeed for the academic interrogation of representation and lived experience in order to redress the way in which my community, as part of both the disability and wider community, is ‘seen’ and how our stories are told. Unequivocally, the treatment of persons – both in reality and in the representation of their stories – has been unethical in terms of diminishing the value and worth of persons with disability, and this film contributes to Nelson’s (2001) resistance to identities that have been perpetuated over time and continue to prevail.

Ethics is a vast subject area to say the least – particularly in these times of immense technological change, specifically in the medical world. In the film world, too, technological change has meant the emergence of user-friendly cameras and accessible platforms for delivery of audio-visual material. The pace with which these new technologies have emerged has seen politicians and law-makers scrambling to create ethical and legal frameworks for the use and distribution of new modes of diagnosis, creation, access and distribution of the products created by these advances.

This project, then – concerned as it is with challenging the representation of persons with genetic differences – sits amidst the unfolding of these ethical dilemmas. The many steps taken to bring the work together have prompted an examination of the ethical frameworks governing the power relations between interviewer and interviewee – or perhaps researcher and subject – and the
construction of a creative work involving persons of differing intellectual capacities. In seeking to challenge the medicalised categorisation and depiction of persons deemed abnormal, the work presents multiple points of view that challenge the very term ‘abnormal’. Susan Baldwin Shafer’s story of ‘discovering’ her genetic difference only after the birth of her daughter signals the ‘failure’ of genetic analysis in terms of her condition not being detected until the age of 27. Susan, by her own admission, asserts that her daughter Shannon is being given stronger foundations than those to which she had access as a child due to the therapies now available, signalling the advances in medicine that now enhance her daughter’s life. For me, these apparent contradictions signal the complexity of our experiences and the necessity of refusing to ‘sit’ in either the ‘medical’ or the ‘social’ model of disability. Ethically, Susan’s story – for me at least – confirmed the distinct lack of experiential knowledge with reference to the delivery of medical diagnoses. Had her mother been given access to pre-natal testing, the results would have been framed within the current disability and risk discourse associated with medical diagnosis, yet she has moved through life, with its challenges and triumphs, and works actively within her community in educating and empowering her peers. I cannot see Susan as unviable or without value as a fellow human being.

Susan’s story stands in stark contrast to Tameka’s. From her first breath until her last in her young, short life, this little girl was at the mercy of a body that brought her pain and suffering. Her short life on the one hand signalled the ‘success’ of genetic diagnosis in that it demonstrated what would be seen as
the highest risk in terms of the conditions to which she was subject; however, the ‘failure’ of medicine to ease her pain and ‘cure’ her is apparent. Tameka’s experience also signalled for me another aspect of ethics in terms of the ‘Golden Rule’ – a principle underpinning many cultural ethical frameworks that sees us ‘Do unto others as you would have them do unto you’ (Flew, 1979: 134). Her life as described by her grandfather was a painful experience for her, with no relief in sight. Her eventual confinement to an aged care facility raised a question for me that challenged the Golden Rule and yet seemed to fit. I wondered who of us would choose to be in an aged care facility as a young person. Yet, in terms of Tameka’s sensory experience in the world, this quiet, peaceful environment brought relief. Interestingly, her young life brought joy to the residents of the facility at a time when she was able to escape the pain her body brought her. In terms of the lengthy battle with her condition and the therapies and medical interventions to which she was subject in order to keep her body alive, I also wondered whether, if I were subjected to a life such as this, I too would wish to be released. Her parents’ final decision to invoke a ‘no resuscitation’ order in the absence of sourcing a means of easing the anguish of her physical body that defied modern medicine seemed in the context of Tameka’s experience to be an appropriate and just action. Meeting with the many people who chose to share their stories confirmed only one thing for me: many more questions would arise with very few easy answers being delivered.

Taking the two brief examples above as reference points, I hope I have illustrated the difficulties I encountered in my creative practice in crafting an ethical framework for my work, giving rise to my contention that the current
referential ethical frameworks we use today for decision-making across myriad areas regarding persons with disability are flawed and in need of serious exploration and redress. Casting our eye back to the very beginnings of what we in the West refer to as ethics has in recent years become the subject of much scrutiny in disability studies, as well as a number of other associated disciplines.

As a starting point for this very brief foray into ethics, I will refer to Stainton’s (2001) discussion about an individual’s capacity for reason being seen as synonymous with that individual’s value and ability to evolve as a good citizen within Aristotelian and Platonism philosophy. Here, Stainton lays the foundations for the ways in which those with intellectual impairment have been regarded as ‘less than’. Within these paradigms, one’s ability to reason – being related directly to one’s intellectual capacity – is seen as fundamental in being able to attain virtuous qualities, enabling one to become a valued member of society. When we in turn highlight a phrase frequently quoted in disability literature from Aristotle’s *Politic*, the challenge of representing persons of physical difference as valuable is made clear with the invocation of a law that decreed ‘that no deformed child shall live’ (McKeon, 1941: 1301). To take the discussion towards that of intellectual impairment – for there is no definite reference to the term or equivalent in the *Politic* – with regard to a person who is unable to display the capacity to reason, Stainton draws parallels between the two. It would seem that the coupling of reason with value has continued to this day, despite evidence that in some cultures what we today term as disability, or more specifically genetic difference, was revered. With this key
foundational element to the construction of ethics as we understand the term brought into relief, it is hardly surprising that we as a society may continue to grapple with questions of what might constitute a viable or valuable life.

Significant challenges to Aristotle’s Nichomachean ethics, outlining what may constitute happiness, goodness and virtue in life (1976), are evident in works by historian Catherine Kudlick (2003) and psychologist Elisabeth Dykens (2006). Kudlick raises questions such as ‘How can we respond ethically to difference? What is the value of a human life? Who decides these questions and what do the answers reveal?’ as she outlines a brief history of disability studies. In closing, she posits that disability ‘reveals and constructs notions of citizenship, human difference, social values, sexuality, and the complex relationship between the biological and social worlds’ (2003: 793).

Dykens (2006) challenges the constitution of a meaningful life, highlighting the exclusion of persons with intellectual impairment in studies concerning happiness and well-being, and stating that, ‘Mental retardation is a diagnosis based on negatives.’ (2006: 185) She then outlines examples of the capacity of people born with intellectual impairment to display virtues such as care and nurturing attitudes to others in need. She also alerts the reader to the medical advances that have been entwined with studies of persons born with genetic difference. These challenges to what constitutes a valuable, virtuous or worthwhile life are a call to revisit our humanity and the ways in which we treat ‘other’ human beings.
Returning to the Golden Rule, a tenet that appears across numerous cultures at this juncture – albeit with some variation – is pertinent, as it too seemed to fall short within my practice when dealing with some aspects of intellectual impairment. My experiences to date indicate a need to align with approaches advocated by writers such as Klotz (2003) in seeking to enter into the world of those born with intellectual impairment before presuming or assuming that we know how ‘they’ operate in the world and how they may wish to be treated. I believe this approach needs to be considered when working with people whose physicality and intellectual disposition sit outside what we may regard as standard or average – or, more specifically, as outside our general experience. How I wish to be treated does not necessarily equate with persons of genetic difference or various other conditions categorised as disabled. What I have come to realise is that underlying this tenet is the notion that how I wish to be treated somehow becomes the authority over how the other person wishes to be treated. My experience of living with Allycia, and having been involved with various disability groups, has demonstrated the need to find out what it is the other person needs first. Certainly when communication occurs non-verbally, this has been a challenge in terms of learning new modes of communication and seeking to understand other ways of being in the world.

A deep commitment to discovering how the other person in our transactions wishes to be treated is perhaps a more ethical approach from my perspective, shaped by my experiences of living, working with and researching disability. This is not to say that the Golden Rule is not an intrinsic foundation for building an ethical framework in the context of my work. In the editing suite, I have been
acutely aware of attempting to represent the subjects of my film as I would wish to be represented – truthfully and with dignity and respect.

Dignity and respect appear to have been lacking when framed within Dykens’ and Kudlick’s accounts of disability, further supporting these assertions within their studies in their parallel fields. This discussion could be – and I posit should be – extended beyond the scant outline offered here. There are significant fractures challenging the very basis of ethical frameworks dealing with disability, and these are increasingly becoming apparent in policy and law-making (Campbell, 2009; Gostin, 2005; Trotzig, 1980; Samaha, 2007), signalling a redress of what constitutes a life worth living. These are complex questions that are not easily answered, but they are questions that each of us may potentially have to answer in the course of our lives.

In confronting these many dilemmas, my turn to other disciplines in search of more explicit frameworks to continue my work resulted in adopting the standpoint outlined by Martin’s ‘knowing bioethicist’ (1999: 316). Martin’s assertions of the skills and qualities required to become a ‘knowing bioethicist’ proved to be invaluable in fashioning a final framework for informing my practice. Her model marries theory with practice, providing a ‘how to’ manual of sorts, and bringing a practicality to the ethical consensus method proposed by the American Society for Bioethics and Humanities (ASBH). As Martin states with regard to an ASBH report recommending the ethics facilitation approach, it ‘specifies the skills, knowledge, and character traits that an ethics consultant should possess’ but ‘does not offer a guide to show how those competencies
should be employed in practice’ (1999: 321). I have included an extract below of how this model works, which has informed my own approach to my work – I substituted myself as the ‘consultant’; my other substitutions are in italics. It is her contention that:

Ethics facilitation (*my research*) involves three types of skills: ethical assessment skills, process skills, and interpersonal skills. Assessment skills enable the consultant to identify and analyze a value conflict or uncertainty and include the abilities to

- discern and gather relevant data …
- assess the social and interpersonal dynamics of the case (*relationship*) …
- identify various assumptions … [and] relevant values …
- Clarify relevant concepts …
- critically evaluate and use relevant knowledge of bioethics, law … institutional policy … and professional codes … (1999: 321)

Above, I included personal codes, disability studies and film theory and practice I likened to my professional code. Further:

- identify and justify a range of morally acceptable options and their consequences … [and] (*for myself, Allycia, my family and community*)
- evaluate evidence and arguments for and against different options. (1999: 320–1)
I ascertained that the process skills described in the following were akin to both production skills and my interactions with my community. The documentation of consultation includes both the audio-visual product and the exegesis:

Process skills allow the consultant to resolve the value conflict or uncertainty, and include the abilities to facilitate meetings, to build moral consensus, to help implement the chosen option, to document the consultation, and to elicit feedback. Building consensus specifically includes the abilities to ‘negotiate between competing moral views’ and to ‘engage in creative problem solving’. Interpersonal skills primarily consist of communication skills and are necessary throughout the consultation. (1999: 321)

To further expound and complicate the project of becoming a knowing bioethicist, Martin cites the nine subject areas cited in the ASBH report where knowledge is required:

- moral reasoning and ethical theory;
- common bioethical issues and concepts (patients' rights, providers' rights and duties, surrogate decision making, end-of-life and beginning-of-life decision making, organ donation, and so forth);
- health care systems (managed care and government based);
- the clinical context (basic medical terms and methods of reasoning, the nature of different medical specialties and health care services, and so forth);
- the local health care institution (the mission statement, institutional structure and services, and so forth);
• institutional policies (regarding advance directives, do-not-resuscitate orders, admissions, discharges, transfers, and so forth);

• patients’ (participants) and staff populations’ [what I and my community perceived to be] general beliefs and perspectives (multicultural awareness);

• relevant codes of ethics, codes of professional conduct, and accreditation standards; and

• relevant health law – I did not refer to health law per se but implications around laws of wrongful life and birth suits have weighed personally and the laws for example about self representation of adults with intellectual impairment and their autonomy. (1999: 321)

In completing the list, Martin cites the character traits of ‘tolerance, patience, compassion, honesty, forthrightness, self-knowledge, courage, prudence, humility, and integrity’ (1999: 321). She then provides a five-step process (1999: 322–4) that incorporates the above information, including the first and final steps of how to open and close a meeting (here I inserted ‘interview’). Steps 2–4 concern gathering facts and identifying interests, identifying and analysing ethical issues, and building consensus and summarising. I used various aspects and variations of these strategies at different junctures throughout the project, depending upon whether I was interviewing, researching, filming, editing or writing.
Viewing this list provided a greater depth of understanding of the task at hand in terms of considering the many issues impacting upon a person born with physical and intellectual impairment, and the responsibility inherent in their representation. The process may seem conflated and somewhat arduous, but considering the fact that I was to become privy to people’s experiences and was to record at times intimate details of their lives for public display, it seemed in order that due consideration be given to the many facets raised in the report and further interpreted by Martin. Conflated and arduous do not sit particularly well with the expediency we as creatives would prefer when commencing our projects; however, it is my experience that articulation of firm guidelines aids in navigating our way. This is not to say a stricter or more rigid set of guidelines would necessarily circumvent misrepresentation, or that consensus about these areas leans more towards subjective opinion-making and shaping, particularly as each of us bring our own beliefs and experiences with us.

In closing, Couser’s (2004) examination of Michael Dorris’s memoir, *The Broken Cord* (1989) provides a concrete example—albeit in the literary form—of the many pitfalls to which autobiographical work as a parent to a child with disability is subject. It would appear that Michael Dorris, the parent of an adopted son who was affected by Foetal Alcohol Syndrome (FAS), crafted his work with an intent not dissimilar to mine in that he wished to raise awareness of the consequences of this particular condition as a contribution towards greater understanding of his son’s place in world. However, in Couser’s (2004)
analysis, the memoir demonstrates a distinct failure to engage in the wider societal concerns associated with the syndrome. Rather than facilitating greater understanding or tolerance of his son’s condition, Couser believes Dorris succeeded in perpetuating the inscription of a “‘vanishing primitive’ which has characterised much ethnography’ (2004: 65–6). Further, he charges that the language used by Dorris ‘echoes that used by colonizers to describe recalcitrant “primitive” people’ (2004: 67). Couser also raises serious concerns regarding Dorris’s son’s ability to provide informed consent due to his intellectually impaired status, and condemns Dorris’s claims to having acquired such consent. Couser’s final verdict about the work – a work that I believe was intended to be written with love and the deep concern of a father for his son’s situation – is that the book ‘echoes rather than revises traditional inscriptions of race and disability’ (2004: 72). This particular case provides a cautionary tale of the precarious nature of imparting our children’s stories on their behalf, and is the subject of further work in the field that I have begun during the course of my thesis.

Given the delicate and contentious terrain in which I quite naively found myself, it has been with a great deal of caution that I have created this piece. It is my hope that the strategies I have employed in returning to our community for approval and the transparency with which I have approached the work have minimised any risk for my daughter, family and our community. The potential implications of working with our community can be both beneficial and laden with risk – and, as asserted in this chapter, there is a need to continue to
participate in ongoing discussions regarding the ethical frameworks within which we both research and practise our craft.
Conclusion

I don’t know what truth is. Truth is something unattainable. We can’t think we’re creating truth with a camera. But what we can do is reveal something to viewers that allows them to discover their own truth.

– Michel Brault

If you, the viewer or the reader, have arrived here and are feeling somewhat confused and a little challenged, then my work is done, for I have found no clear-cut answer to the many questions asked within this work; I simply have more questions. However, I have arrived at a place of greater understanding of the complexity of our species and our society – and have developed a deep respect for, and anticipation of, learning more about what I do not know.

The challenges confronting people living with disability are many, and require redress across the social, political, medical and legal landscapes that continue to exclude and refuse recognition of difference as valuable, worthwhile and intrinsic to the well-being of us all. I have embarked upon this project with the intent of furthering the work of the social model of disability in the opening up of spaces for challenging the social construction of disability, and hope it contributes to further discussions of how to best forge our way into the future. As Samaha (2007) articulates in his work, the social model must now be transformed into the stuff of policy-making that takes into account the lived
physicality and assistance required for those living with disability, with respect for their need for dignity and right to autonomy.

It must be said that being given the news that one’s child carries a genetic abnormality, in this historical moment, has the capacity to profoundly affect how one comes to view one’s own child, and I would wager that it is a unique experience for each of us who have encountered this situation. However, in the absence of stories relating to the lived experience and potentiality of other children born with similar conditions, we are only being given a partial story upon which to base our hopes and fears for the future. It is my contention that works such as 18q-: A Different Kind of Normal have a place in accompanying medical diagnoses in a bid to provide a fuller picture of who our children may become. I am hopeful, too, of finding ways to work towards enhancing how medical diagnoses are delivered in this realm.

I am pleased that as a result of embarking upon this project I have had the opportunity to speak in a number of arenas and to share our Chromosome 18 stories with many who were unaware of the condition. This has been a valuable outcome for us as a community.

I believe that my work in developing an ethical framework and structure for the film and exegesis, by using the basic documentary framework outlined by Gross et al. (1988) as a foundation, and further developing and extending it to include Martin’s framing of a ‘knowing bioethicist’, contributes to both complicating and simplifying the ethical dilemmas encountered by researchers
and filmmakers on a regular basis. The approach may be seen as far more complex than that offered by the documentary theorists; however, when framed within the risk-laden contexts described by Blackwell (2004) and Couser (2000), the drilling down and articulating of an ethical standpoint at the outset of a project may well minimise the diverse array of ethical dilemmas that can ensue when there is inadequate preparation and insufficient consideration.

The use of Bhaskar’s Critical Realism approach in endeavouring to contest and problematise the category of disability may prove useful for future interrogation and representation of persons living with disability, particularly in the realm of autobiographical and biographical works. This experience as both subject and filmmaker has, I believe, enhanced my practice immeasurably, by furthering my understanding of what ‘it’ is I am actually asking of an interviewee when they sit before the lens. In this respect, I can now speak openly and honestly about the difficulties that may confront a subject, and truly empathise with their potential vulnerability and discomfort. I have had to learn to sit comfortably facing myself – who is at once the same but an ‘other’ in terms of space and temporality – and have drawn certain parallels and analogies with this experience, and my work and research concerning another ‘other’. It is my belief this is a worthwhile experience for any documentary filmmaker concerned with bringing people’s intimate stories to the screen, and could also be a worthwhile exercise in terms of a short film project for film and television students.
In spite of the criticisms brought forth in this thesis, I believe there is much to be hopeful about with regard to the changing face of disability in film and television, particularly in the realm of the fictional film with the emergence of filmmakers like Adam Elliot and Elissa Down. Their personal experiences with disability have been translated into highly successful works, and demonstrate the way in which the social construction of disability can be contested powerfully in fictional works – perhaps signifying a further extension in some respects to Grierson’s (1932) ‘creative treatment of actuality’.

In terms of my own work, I have realised the different functions provided by making documentary versus fictional works. Through this project, and the time and space it has demanded in terms of self-reflection, these two markedly different approaches have served to resolve the same issue – that of finding new ways to live within a disability context. The fictional realm has offered me a space to re-imagine our lives in the absence of story. The writing and production of fictional film has been cathartic, as I have unleashed my emotions upon the script and worked through the many emotions I experienced in those early years of Allycia’s life. The making of this documentary has demanded a much more restrained approach and another drive as its premise – my desire to contribute and share stories of our community as a social justice project rather than a personal anecdote about our lives.

It is a difficult proposition to critique one’s own film, and I am particularly critical of my own work. The film falls short technically at many levels, with poor lighting and sound diminishing the quality of some of the interviews. There are
also many areas where I would have liked to have included other material, including re-enactments. From my personal perspective, intercuts of some of the fictional films that have inspired me would have enhanced the visual appeal of the film; however, they also would have broken the budget. However, insofar as film can only represent a version of reality, it can also function as an invitation to learn and know more, and in this respect I believe the work succeeds. The characters in the film are strong and delightful at times, and the honesty that is delivered in the interview material is enlightening. It has been an honour to bring these young people and their families to the screen and, while meeting them on screen is merely a shadow of how delightful our community is, the work testifies to our presence and the beauty and support a community can bring.

It has been an extraordinary experience to view our lives and shape those experiences into a narrative that at times does resemble the hero’s journey of being faced with new challenges, finding solutions and overcoming challenges, achieving a goal and then being faced with the next set of challenges. Perhaps life and art are truly reflective and interchangeable.

With the film now complete, I feel the contribution of the work in attesting to the Chromosome 18 community’s place among us has been achieved. I look forward to progressing opportunities at specific film festival events and the possibility of broadcasting potential. The landscape is unknown here, for in resisting the stereotypical portrayal of disability and the idealising of the heroic disabled, the film sits outside the drama and spectacle that have become the
fodder of mainstream media. Feedback received from initial screenings of the film for students at QUT’s School of Learning and Professional Studies by Dr Linda Gilmore, lecturer in educational and developmental psychology, has been positive in terms of students’ perceptions of intellectual impairment being challenged and the acquiring of new knowledge in the field of disability. I am hopeful that the work can be used to challenge the very limited views that exist about people living with intellectual impairment in learning and teaching environments. I believe the work will at the very least find a place within our wider disability community and those we live, liaise and work with as a tool for demonstrating the richness that life with disability can offer.

At the heart of the work have been my three children, most particularly Allycia, and it is my sincere hope that she will always be happy with the film we have produced and that she may one day choose to pick up a camera and fashion her own version of what life with 18q- is really like. My ultimate hope for the work rests in its capacity for inspiring conversation – Buber’s notion of dialogue that creates the spaces in between where I and thou may become intimately involved in the sharing of ideas and the many possibilities those conversations may bring.
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**Films and Documentaries**

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*Axe in the Attic* 2007, directed by Edward Pincus.


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*Best Boy* 1979, video recording, directed by Ira Wohl, Only Child Motion Pictures.

*Best Man: Best Boy and All of Us Twenty Years Later* 1997, directed by Ira Wohl, Only Child Motion Pictures.


*The Boy Inside* 2007, directed by Mark Kaplan, MSK Productions.

*The Civil War* 1990, television mini-series, PBS, directed by Ken Burns.

*Cunnamulla* 2000, video recording, directed by Dennis O’Rourke.

*Diaries* 1982, video recording, directed by Edward Pincus.

*18q – A Valuable Life* 2011, written and directed by Veronica Wain.

Forrest Gump 1994, film, written by Eric Roth, directed by Robert Zemeckis, Paramount Pictures.

Germany, Pale Mother 1980, video recording, written and directed by Helma Sanders-Brahms.

The Gleaners and I (Les Glaneurs et la glaneuse) 2000, DVD, directed by Agnes Varda.

Harvie Krumpet 2003, written and directed by Adam Elliot, produced by Melanie Coombes, Icon Entertainment.


Laughing at the ‘Disabled’ [later changed to Laughing with the ‘Disabl...]

2007, produced by Michael Noonan, PhD documentary, Queensland University of Technology.

Mary and Max 2009, film, written and directed by Adam Elliot, produced by Melanie Coombes, Monster Distributes.


Murderball 2005, film, directed by Dana Shapiro and Henry Rubin, MTV Films.

Nanook of the North 1922, directed by Robert J Flaherty.

The Other Sister 1999, DVD, written and directed by Garry Marshall, Touchstone Pictures.

Panola 1965, video recording, directed by Edward Pincus and David Neuman.

Refrigerator Mothers, 2003, DVD, directed by David Simpson, Kartemquin Films.

Roger and Me 1989, film, written and directed by Michael Moore, Dog Eat Dog Films.
Sans Soleil 1982, video recording, directed by Chris Marker.

Sherman’s March 1994, video recording, written and directed by Ross McElwee.

Shorn 2006, film written and produced by Veronica Wain and directed by Martha Goddard


Time Indefinite 1993, video recording, written and directed by Ross McElwee.


Titticut Follies 1967, video recording, directed by Frederick Wiseman.

Tongues Untied 1990, semi-documentary, directed by Marlon Riggs, produced by Brian Freeman.

Troublesome Creek 1995, video recording, written and directed by Steven Ascher and Jeanne Jordan.

What the Bleep Do We Know? 2004, DVD, written, directed and produced by William Arntz, Betsy Chase and Mark Vicente, Roadside Attractions.

Appendix 1: Participant Information Sheet and Consent Form (QUT)

Participant Information Sheet

‘18Q – An examination of disability and media representation’

Veronica Wain
T: 07 3848 7075
M: 0433 433 204
E: veronica_wain@yahoo.com.au

Description

This project is being undertaken as part of a PhD project for Veronica Wain at Queensland University of Technology.

The purpose of this project is to raise community awareness of Chromosome 18 syndromes and examine the way in which people living with disability are represented in the media.

The research team requests your assistance in identifying key issues that have affected your lived experiences as a person or family living with disability.

Participation
Your participation will involve the filming of interviews or the filming of attendees’ participation in meeting activities, during the course of The Chromosome 18 Registry & Research Society (Aust) Inc Annual Family Meeting 2005 taking place in Cronulla, Sydney.

The audio/video recordings may be included in the documentary ‘18Q’, may be used in the compilation of an instructional and/or educational aide and will be released for public viewing. Written transcripts maybe used in documentation and within theoretical frameworks within the thesis component of the work. Should you wish to contribute your viewpoints, but do not wish to be filmed, please feel free to submit your thoughts to the above email address and advise the recipient of your confidentiality requirements.

**Expected benefits**

It is expected that this project will be of benefit to you in terms of raising community awareness of the Chromosome 18 syndromes and presents an opportunity to show an alternate view of living with disability.

**Risks**

There are no additional risks associated with your participation in this project.
Confidentiality

During the video recording it will not be possible to maintain your confidentiality or anonymity, however should you wish your family name to be withheld, your wish will be adhered to upon request.

Voluntary participation

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT.

Questions / further information

Please contact the researchers if you require further information about the project, or to have any questions answered.

Concerns / complaints

Please contact the Research Ethics Officer, at Queensland University of Technology, on (07) 3864 2340 or +61.7.3864-2340 or ethicscontact@qut.edu.au if you have any concerns or complaints about the ethical conduct of the project.
Consent Form
‘18Q – An examination of disability and media representation’

Veronica Wain
T: 07 3848 7075
M: 0433 433 204
E: veronica_wain@yahoo.com.au

Statement of consent

By signing below, you are indicating that you:

• have read and understood the information sheet about this project;
• have had any questions answered to your satisfaction;
• understand that if you have any additional questions you can contact the research team;
• understand that you are free to withdraw at any time, without comment or penalty;
• understand that you can contact the research team if you have any questions about the project, or the Research Ethics Officer at the Queensland University of Technology on 3864 2340 or +61.7 3864-2340 or ethicscontact@qut.edu.au if you have concerns about the ethical conduct of the project;
• understand that the project will include audio and/or video recording; and
• agree to participate in the project.

Name:

Signature:

Date:
Appendix 2: Participant Information Sheet and Minor Consent Form (QUT)

Information Sheet

‘18Q – An examination of disability and media representation’

Veronica Wain  
T: 07 3848 7075  
M: 0433 433 204  
E: veronica_wain@yahoo.com.au

Description

This project is being undertaken as part of a PhD project for Veronica Wain.

The purpose of this project is to raise community awareness of Chromosome 18 syndromes and examine the way in which people living with disability are represented in the media.

The research team requests your assistance in identifying key issues that have affected your lived experiences as a person or family living with disability.
Participation

Your participation will involve the filming of interviews or the filming of attendees’ participation in conference activities, during the course of the Chromosome 18 Conference, 2007 taking place in Plymouth, USA.

The audio/video recordings may be included in the documentary ‘18Q’, may be used in the compilation of an instructional and/or educational aide and will be released for public viewing. Written transcripts may be used in documentation and within theoretical frameworks within the thesis component of the work. Should you wish to contribute your viewpoints, but do not wish to be filmed, please feel free to submit your thoughts to the above email address and advise the recipient of your confidentiality requirements.

Expected benefits

It is expected that this project will be of benefit you in terms of raising community awareness of the Chromosome 18 syndromes and presents an opportunity to show an alternate view of living with disability.

Risks

There are no additional risks associated with your participation in this project.
Confidentiality

During the video recording it will not be possible to maintain your confidentiality or anonymity, however should you wish your family name to be withheld your wish will be adhered to upon request.

Voluntary participation

Your participation in this project is voluntary. If you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty. Your decision to participate will in no way impact upon your current or future relationship with QUT.

Questions / further information

Please contact the researchers if you require further information about the project, or to have any questions answered.

Concerns / complaints

Please contact the Research Ethics Officer on 3864 2340 or ethicscontact@qut.edu.au if you have any concerns or complaints about the ethical conduct of the project.
Minor Consent Form

‘18Q – An examination of disability and media representation’

Veronica Wain
T: 07 3848 7075
M: 0433 433 204
E: veronica_wain@yahoo.com.au

Statement of Parent/Guardian consent

By signing below, you are indicating that you:

- have read and understood the information sheet about this project;
- have had any questions answered to your satisfaction;
- understand that if you or your child have any additional questions you can contact the research team;
- understand that you or your child are free to withdraw at any time, without comment or penalty;
- understand that you or your child can contact the research team if there any questions about the project, or the Research Ethics Officer at the Queensland University of Technology on (07) 3864 2340 or +61.7.3864-2340 ethicscontact@qut.edu.au if they have concerns about the ethical conduct of the project; and
- agree to your child’s participation in the project.

Full Name of Child/Children/Individual…………………………………………………………

Name:

Signature:

Date: :