

Bend, Break or Defend

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Abstract

The autobiographical documentary film *18q – a valuable life* (working title), is a practice-based research project within Griffith University's Queensland College of Arts and furnishes another chapter in challenging mainstream media's representation of persons identified as disabled.

My work, taking the camera into our domestic space, and indeed our emotional space, in portraying the everyday, lived experience of my family's lives since my youngest child, Allycia's birth in 1995, endeavours to offer an alternate reading of disability as "other". Born with a rare genetic condition known as chromosome 18 whereby part of her 18th chromosome is missing, Allycia, from the moment of diagnosis was labelled disabled and is categorised as physically and intellectually impaired.

The viewing of a constructed version of my life, re-framed by the experience of living with Allycia, labelled disabled, has provided a unique opportunity to explore the editing process and its role in re-framing and re-visioning the disabled as "other". The project has prompted a re-examination of self and the ethical framework used in determining how some boundaries needed to be breached and how some, out of respect for family members and members of our community, remained in tact and in some instances, resulted in footage being discarded.

Keywords: disability, ethics, documentary

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Introduction

From the moment the camera became a partner in telling our story, Ken Burns' articulation of the documentary and his defining of style as a "description of how one solves the problems of production" was apparent.¹ The problems of production have been many, particularly in the realm of shaping an ethical framework to inform character construction, thematic concerns and the editing process. Burns' assertion too 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"² has been the cause of interminable insomnia! Yes and no, in the case of *18q* are inextricably entwined with Nichols' identification of the complexity of image making in the documentary form, most particularly his concerns with "the nature of consent", "the right to know versus the right to privacy" and "the responsibilities of the filmmaker to his or her subject as well as audience"³. These concerns are magnified exponentially when dealing with a marginalized and vulnerable group of people subjected to a history of misrepresentation and a collective dehumanizing and diminishing of their very existence. So too, bringing my family and myself into view, exposing our experiences and emotions to an unknown and unknowing public is fraught with ethical dilemmas. These dilemmas are not unique and are discussed at length in Katz and Katz's⁴ work concerning consent, disclosure, motive and construction in the autobiographical documentary, however consent and disclosure take on more complex and problematic dimensions as parent of a person whose capacity to give informed consent is compromised by varying levels of intellectual cognition.

As a person whose intellectual capacity can be categorized within a predetermined parameter known as average or within normal range, and as mother to a child born with intellectual and physical impairment, guardianship and advocacy are guiding principles in fashioning the final cut. I felt conflicted on many occasions as my desire to protect my family oftentimes butted against the desire to make a film that would inspire conversation and challenge what I perceived as a collective diminished valuing of people born with physical and intellectual difference. This perception, as a mother of a disabled child is explored in Landsman's "Mothers and Models of Disability"⁵ whereby we as mothers,

collectively harbour fears about how our children will be received into society and battle with the impulse to protect them from hurtful teasing and ridicule.

These anxieties, together with my intimate relationships with most of the subjects, have at times threatened the demise of the work due to my fear of “getting it wrong”. The “it” is complex – it includes my fear of how an audience views members of the chromosome 18 community, my family and myself and how we will be judged. The fear of not delivering on the promise of this “other” vision of disability– a vision that challenges the stereotypical and negative image making of lives lived with intellectual and physical impairment - was at times crippling. The many selves that reside within me: mother, sister, daughter, filmmaker, activist, academic have clashed and colluded in the desire to say something about our lives and where we find ourselves in the milieu of lives categorized as disabled in a society where an ever present drive towards an imagined perfecting of the physical and intellectual self is held up as ideal. I have over time, at least to some extent, reconciled many of those competing voices behind and in view of the camera, however they have re-emerged with equal voracity during the final edit as I, with my editor endeavour to bring a coherent and engaging film to fruition.

To have begun this project was to embark upon what Carter describes as an “intellectual adventure peculiar to the making process”⁶. Editing *18q*, has proven the most challenging so far in terms of the construction of an intelligible narrative and in discerning the most ethical and respectful means of presenting images and experiences of society’s arguably, most vulnerable group. Given the scarcity of documentary films dealing with the world of the intellectually impaired and the lack of well articulated ethical parameters to guide filming and research in this area, *18q* sits at the ethical edge of editing.

The ethical edge of editing

Access to equipment, personnel and finances is a creative endeavour in itself as a student filmmaker. Managing these issues resulted in enlisting a number of cinematographers and three editors in bringing the film to fruition with each person bringing a different vision to the work. My editorial relationships have been built upon friendship resulting in

a heightened awareness of Cunningham's assertion that "With every cut, the editor makes conjectures and statements about the person's character as an empathetic person, an editor cannot help but be distracted by the nagging question, 'What will the subject think of this portrayal?'"⁷ The subjects are all known to me at an intimate level albeit at varying levels of intimacy ranging from familial relationships to close friendships and professional relationships, so how they react to their portrayals is important to me.

Managing my son's refusal to be interviewed on camera has been an absence demanding attention, for this absence, together with his obvious discomfort when on those occasions the lens has penetrated his personal space will, if left unexplained, have the potential to construct his character as aloof and uncaring, which is in itself an "untruth". Katz and Katz⁸ discussion of appropriate disclosure furnished a foundation for me in navigating through this dilemma. Perhaps it is more the mother in me than the filmmaker that does not wish to see my son misjudged in the public domain; however this concern, together with others, has been discussed with my supervisory team as well as the chromosome 18 community.

Taking various cuts of the work in progress back to our community was to collaborate with other members in guiding the building of an ethical framework. Whilst national ethical guidelines⁹ relating to research and matters of consent go some way to safeguarding the rights of those with varying levels of intellectual impairment, I felt some ambiguities were left open to interpretation –interpretation I was unwilling to make on my own without informed consent from the group I was claiming to represent. I referred often to Katz and Katz¹⁰ discussion about ethics and perception as a foundation to build upon, in particular their work concerning Ira Wohl's film *Best Boy*¹¹

This concern with informed consent was not unfounded, becoming the subject of a public and somewhat vitriolic debate when another PhD film project entitled "Laughing at the Disabled: creating comedy that confronts, offends and entertains" was criticised in *The Australian*¹² by two academics, Drs John Hookham and Gary MacLennan in 2007, who at that time were supervising this project. The furore brought many issues into the public

domain however the most pertinent in reference to this project, at least, was the divided opinion surrounding the capacity of individuals with intellectual impairment to discern issues of consent. How do we, as a society grant autonomy and the right to make decisions to those with intellectual impairment yet continue to safeguard against their potential exploitation? Who do we entrust with these responsibilities and how are judgements made about what can be considered acceptable or not, on their behalf, or not? These are complex questions and will I believe, increasingly enter the public arena as the disability community continues to become more visible. I did not wish to carry this responsibility alone and turned to our immediate community for feedback on a regular basis to at least ensure a measure of agreement that the film reflected appropriate ethical standards and respect for the subjects.

In spite of these measures and safeguards, my editor and I continue to approach the work cautiously. The way the frames flow, the language used and narrative construction, place us at the edge of ethical practice as we make critical decisions about which boundaries we need to bend, break or defend.

Bending

Bending boundaries is central to the film in that if the portrayal of our lives and experiences is to be completely truthful, it would be a long sequence shown in chronological order and would result in a somewhat boring representation of our reality. In truth, our lives are generally mundane and relatively uneventful – this life can hardly be described as riveting drama worthy of screen time. However when sorting through the footage of the events and moments that have shaped our lives some engaging sequences have emerged and been constructed. So we have had to bend the truth somewhat in similar ways to other documentary filmmakers in a temporal sense by taking those sequences and constructing a narrative to ensure the material has the potential to achieve a level of engagement with an audience.

This engagement in part will be achieved by the opportunity to meet subjects who until now have remained invisible. People born with chromosome 18 conditions are rare and

occupy very little space and time in the world of film or television. Interviewing some of the young adults affected with chromosome 18 conditions was tempered with the knowledge of unequal power relations between them as subjects and myself as enquirer. This inequality was perceived at a number of levels including their inexperience with the medium, our age difference and the very fact I held the camera subjecting them to its gaze whilst I could remain invisible.

My greatest challenge in contesting boundaries was the level of questioning I engaged in with Kathryn and Martin, a young couple, both born with chromosome 18 deletions, who have fallen in love. I wanted to share in their experiences and was keen to reveal the beauty of their relationship. One of the most contentious issues I have found as a parent of a child with intellectual impairment is that of whether she should become a parent or not. Questions about the intellectually impaired and their capacity to be responsible parents are not easily answered. Sexuality too, is not easily brought into discussion with emerging studies now exploring the difficulties we as a society have in broaching these issues. I was keen to show Kathryn and Martin's capacity for decision making and determined to treat them with the same respect I have for my other children who are similar in age. Whilst I knew I had the freedom to retain or discard footage in the final cut, I still hesitated in asking them if they had discussed the possibility of having children. I felt in some way I might violate their right to privacy and for me conducting an ethical process is as important as delivering an ethically sound film. Martin answered the question with a great sense of maturity stating they had discussed children but no decision had been made. This response left me with a sense of respect, admiration and relief. I could now include footage that reflected part of my vision for the film – an articulate response from a young man whose medical diagnosis would never have delivered the promise of the person sitting in front of me.

I have included a clip from the interview where Kathryn and Martin kiss, and I pan to Allycia watching on. She reacts with a kind of feigned shock, resulting in laughter from Kathryn, Martin and myself. This sequence in retrospect may be considered to be either bending or breaking boundaries in light of Katz and Katz¹³ discussion of disclosure and the close proximity I have with my subjects. I have asked myself why this moment of

open affection is so significant – would it have been as significant if I had filmed my other daughter or son similarly? If not, why not? Why is it such an ethical dilemma for me? On the one hand it was a very personal moment and I felt voyeuristic. I believe however that I am a product of not having been exposed to people of difference freely expressing and being who they are – what I saw that day was new to me and I felt both self conscious and privileged to be part of the moment.

In other respects I have in a sense bent or played with the documentary form by way of including a 3D animation sequence to visually communicate the medicalised description of chromosome 18 conditions. Other devices, such as the incorporation of sequences from short form fiction films I have made, add to the world of the film and endeavour to create a vision whereby creative responses to seemingly insurmountable situations can often times result in unexpected and quite delightful outcomes.

Breaking

Whilst I have spent some considerable time behind the scenes writing and producing short films, my greatest personal challenge in the initial stages of making the documentary was my aversion to being in front of the camera and it soon became apparent that the greatest barrier to telling the story was me. Not only was I keen to avoid being viewed, I also struggled to embrace an expositional style of narration due to a personal prejudice towards the practice, seeing it as a dated approach to the genre. I wanted to tell the story through others' experiences, somehow seeking some universals in the disability experience. I also saw this approach as a safeguard against the film degenerating into a navel gazing exercise.

My breakthrough, happened in a most unexpected way, when after enlisting the help of a fellow filmmaker to shoot me packing up my family home, I crumbled in front of her, and the camera. My emotional state was fragile and as I began to share my feelings with my friend the camera became inconsequential as a flood of tears and emotion overcame me. This happening has served me and the film well for two reasons. Firstly I was now positioned in the same “place” as the subjects in the film. In essence, my breaking down,

the penetrating of my privacy during a difficult and emotional time enabled me reconcile an internal ethical dilemma – that of asking others to reveal themselves in the presence of the camera – I was now one of them.

The second significant outcome was the opportunity to view myself “in the past” at a time when life felt overwhelming. Sitting with those images in the editing suite has been challenging and surreal. Becoming one’s own observer is a strange sensation. That person I now see is “an other” and although initially I felt a great degree of self consciousness watching that other, I now view her with compassion and am reminded that all that is passes, giving way to other possibilities.

Other possibilities exist too in the hopes I have for the film in breaking the most fundamental barrier this film endeavours to shatter – rendering this previously invisible group, visible.

Defending

In endeavouring to render the invisible visible, I have in many respects defended more boundaries than I have contested when considering the work within the greater context of powerful and confronting documentaries. *Murderball*¹⁴ for example, a contemporary documentary exploring disability, contests stereotypical portrayals of men in wheelchairs, exposing their private lives, most particularly their sexuality. In defence of my hesitancy and what may be perceived as not going far enough I suggest that the subjects in *Murderball* differ from those in *18q*. The most significant difference, one blurred both in reality and in media portrayals of disability, is that those subjects in *Murderball* have acquired disability as opposed to congenital disability. Whilst it seems to be a common assumption and experience that the acquiring of a disability equates with the loss of quality of life for those affected, this is not necessarily the experience of people born with congenital disability. Allycia to date has not expressed loss; the expression of her life suggests otherwise. She appears to enjoy her life for the most part. So too Kathryn and Martin are in the midst of having found their life partner and are planning a future with many possibilities.

Another significant difference is the intellectual capacity of those in *Murderball*¹⁵ and *18q*, signifying differing levels of engagement with issues around sexuality and informed consent. I did not feel comfortable broaching parents or young adults about issues of sexuality to any great extent on camera. This is new territory for us as a community and I am keenly aware of how difficult it is to navigate our way through discussions about sexuality and believe this knowledge has hampered my willingness to explore this area more fully within the context of the film.

My hesitancy in crossing these lines was also hindered by the knowledge that sexuality and intellectual impairment have been historically misunderstood and uncomfortably paired.¹⁶ Image making in this realm needs to be carefully considered given the still prevalent prejudicial and somewhat misinformed opinions that continue to proliferate.¹⁷ My decision to discard footage of an interview with a young woman from our community where her delightful, flirtatious personality is evident as she interacts with my cinematographer reflects (perhaps) an overriding protective impulse that has informed the film. This fun and spontaneous sequence, in the absence of accompanying footage and background to place her within her own experiential context, had the potential to perpetuate misinformed, stereotypical views expressed in the aforementioned works and so was abandoned at this time.

The sensitivity surrounding sexuality and the possibility of our children choosing to have children is also made evident in the film when questioning Martin's father. I was given an unequivocal "no, not going there" in response to my question about whether or not grandchildren have been discussed with Martin and Kathryn. Clearly, this issue is a private issue for the family and not for public discussion. I am comfortable with this response and believe it demonstrates our overriding impulse to protect our children and our privacy. The problem here however is how to move these issues into the public arena for discussion, issues that are increasingly subject to legislation and litigation without compromising our right to privacy. The audience is given a glimpse into the complexity of our world and left to ponder the issue.

Another significant boundary defended was my son's right to privacy which has posed some problems in narrative construction, disclosure and matters of consent. The first obstacle to his inclusion in the film was his refusal to be interviewed. I had an initial impulse to somehow convince or persuade Adam to be more vocal, however to have embarked upon a manipulative or coercive exercise such as this would have compromised the ethical framework I was so keen to work within and was to be guarded against when examined within Katz and Katz's¹⁸ framework. Sequences of Adam expressing his need for privacy are included in the cut at this stage and are coupled with voice over as a device to make him visible within our family's life and to assert his right to privacy.

Conclusion

The making of the film succeeds in breaking the most fundamental barrier confronting people born with chromosome 18 conditions – a work now exists testifying to their existence. However it may be said that few other barriers appear to have been penetrated to any great degree, rather topics for discussion have been raised without definitive reply. This may be an answer in itself - the issues raised are complex and defy resolution within a 60 or 90 minute format.

We in the chromosome 18 community are creating new narratives and new histories – hopefully. Our children participating in everyday life at home is a relatively new phenomenon historically – it is only in recent times that institutions have lost their supremacy in caring for society's so called defectives. Issues including sexuality, marriage and parenthood for those who are intellectually impaired are new for us and demand discussion. The production and in particular the editing of *18q – a valuable life* demonstrates the difficulty in determining how those discussions should take place. My hope is that the film initiates conversations that work towards enabling all of us to move forward in exploring the issues respectfully, honouring all of our humanity.

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Endnotes

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