

Able to live, laugh and love

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Published

2008

Journal Title

Media Culture Journal

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M/C Journal, Vol. 11, No. 3 (2008) - 'able'

Able to Live, Laugh and Love

<http://journal.media-culture.org.au/index.php/mcjournal/article/view/54>

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The autobiographical documentary film “18q – a valuable life”, is one attempt to redefine the place of disability in contemporary western society. My work presents some key moments in my life and that of my family since the birth of my youngest child, Allycia in 1995. Allycia was born with a rare genetic condition affecting the 18th chromosome resulting in her experiencing the world somewhat differently to the rest of the family. The condition, which manifests in a myriad of ways with varying levels of severity, affects individuals’ physical and intellectual development (Chromosome 18, n. pag.). While the film outlines the condition and Allycia’s medical history, the work is primarily concerned with the experiences of the family and offering an alternate story of disability as “other”. Drawing on Rosemarie Garland Thomson’s notion of shape structuring story (“Shape”) and Margrit Shildrick’s discussion of becoming vulnerable as theoretical foundations, I reflect on how the making of the film has challenged my previously held views about disability and ultimately about myself.

The Film & Disability

“18q – a valuable life” introduces a new, previously “invisible” shape in the form of bodies coded as Chromosome 18 to the screen. The initial impulse to make the film was driven by a need to provide a media presence for a rare genetic condition known collectively as Chromosome 18 (Chromosome 18, n. pag.) where previously there was none. This impulse was fuelled by a desire to tell a different story, our story; a story about what life can be like when a child with intellectual and physical impairment is born into one’s family. This different story is, in Garland Thompson’s terms, one that “insists that shape structures story” (114) and endeavours to contribute to recasting disability “as an occasion for exuberant flourishing” (Garland Thompson 114).

The categorisation and depiction of people with disability in western society’s media have been scrutinised by many writers including Mitchell and Snyder (“Representations”; “Visual”), Oliver and Norden who point out that negatively charged stereotypical representations of the disabled continue to proliferate in the mediasphere. Englandkennedy for example examines the portrayal of the new disability classification Attention Deficit Disorder and is highly critical of its representation in programs such as *The Simpsons* (1989-2008) and films such as *Pecker* (1998). She asserts, “few media representations of ADD exist and most are inaccurate; they reflect and reinforce social concerns and negative stereotypes” (117) to the detriment of the condition being better understood by their audiences. However,

Englandkennedy also identifies the positive possibilities for informed media representations that offer new models and stories about disability, citing works such as *Children of a Lesser God* (1986) and *The Bone Collector* (1999) as examples of shifts in fictional story telling modes.

There are also shifts in recent documentary films such as *My Flesh and Blood* (2004), *Tarnation* (2003) and *Murderball* (2005) which provide insightful, powerful and engaging stories about disability. I suggest however that they still rely upon the stereotypical modes identified by numerous disability studies scholars. For example, Darke's (n. pag.) heroic mother figure and disabled outsider and victim are depicted in the extreme in *My Flesh and Blood* and *Tarnation* respectively, whilst *Murderball*, as powerful as it is, still constructs disability as "something" to be overcome and is celebrated via the character construction of the "super-crip" (Englandkennedy 99). These stories are vital and insightful developments in challenging and re-shaping the many stigmas associated with disability, but they remain, for the most part, inaccessible to me in terms of my place in the world as a person parenting a little girl with physical and intellectual impairment.

Able to Live

The opening of the film features footage of my two older children Adam and Kristina, as "normal", active children. These idyllic images are interrupted by an image of me by Allycia's bedside where, as an infant, she is attached to life saving machines. She is at once "othered" to her active, healthy siblings.

Her survival was reliant, and remains so, albeit to a much lesser extent, upon the intrusion of machines, administering of medication and the intervention of strangers. The prospect of her dying rendered me powerless, vulnerable; I lacked the means to sustain her life. To hand over my child to strangers, knowing they would carve her tiny chest open, suspend the beating of her already frail heart and attempt to repair it, was to surrender to the unknown without guarantees; the only surety being she would cease to be if I did not.

Allycia survived surgery. This triumph however, was recast in the shadow of abnormality as outlined in the film when genetic screening of her DNA revealed she had been born with a rare genetic abnormality coded as 18q23 deletion. This information meant she was missing a part of her eighteenth chromosome and the literature available at that time (in 1997) gave little cause for hope – she was physically and intellectually retarded. This news, delivered to me by a genetic counsellor, was coupled with advice to ensure my daughter enjoyed "quality of life".

The words, "rare genetic abnormality" and "retarded" succeeded in effectively "othering" Allycia to me, to my other two children and the general population. My knowledge and experience with people with genetic abnormalities was minimal and synonymous with loss, sadness, suffering and sacrifice and had little to do with quality of life. She was frail and I was confronted with the loss of a "normal" child that would surely result in the "loss" of my own life when framed within this bleak, imagined life that lay before me; her disability, her otherness, her vulnerability signalled my own.

As unpalatable as it is for me to use the word monstrous with reference to my daughter, Shildrick's work, aligning the disabled experience with the monstrous and the possibility of becoming via a refiguring of vulnerability, resonates somewhat with my encounter with my vulnerable self. Shildrick proposes that "any being who traverses the liminal spaces that evade classification takes on the potential to confound normative identity" (6). As Allycia's mother, I find Shildrick's assertion that the monstrous "remains excessive of any category, it always claims us, always touches us and implicates us in its own becoming" (6) is particularly pertinent. This is not to say that Shildrick's notion of the monstrous is an unproblematic one. Indeed Kaul reminds us that:

to identify disabled bodies too closely with the monstrous seems to risk leaving us out of universal, as well as particular, experience, entirely in the figurative. (11)

Shildrick's notion of the universality of vulnerability however is implicit in her reference to that which confounds and disturbs us, and it is an important one. Clearly Allycia's arrival has claimed me, touched me; I am intimately implicated in her becoming. I could not have anticipated however the degree to which she has been intertwined with my own becoming. Her arrival, in retrospect crystallised for me Shildrick's proposition that "we are already without boundaries, already vulnerable" (6).

The film does not shy away from the difficulties confronting Allycia and my family and other members of the chromosome 18 community. I have attempted however to portray our environment and culture as contributing factors and challenge the myth of medicine as a perfect science or answer to the myriad of challenges of navigating life with a disability in contemporary society. This was a difficult undertaking as I did not want the work to degenerate into one that was reliant on blame or continued in the construction of people with disability as victims. I have been mindful of balancing the sometimes painful reality of our lives with those moments that have brought us a sense of accomplishment or delight.

Part of the delight of our lives is exemplified when my sister Julie articulates the difference in Allycia's experiences as compared to her own nine year old daughter, Lydia. Julie succeeds in valorising Allycia's freedom to be herself by juxtaposing her own daughter's preoccupation with "what others think" and her level of self consciousness in social contexts. Julie also highlights Lydia's awareness of Allycia's difference, via narration over footage of Lydia assisting Allycia, and asserts that this role of becoming a helper is a positive attribute for Lydia's development.

Able to Laugh

Including humour in the film was a vital ingredient in the reframing of disability in our lives and is employed as a device to enhance the accessibility of the text to an audience. The film is quite dialogue driven in furnishing background knowledge and runs the risk at times, when characters reveal some of their more painful experiences, of degenerating into a tale of despair. Humour acts as device to lift the overall mood of the film.

The humour is in part structured by my failures and incompetence – particularly in reference to my command (or rather lack) of public transport both in Australia and overseas. While the events depicted did occur – my missing a ferry and losing our way in the United States – their inclusion in the film is used as a device to show me, as the able bodied person; the adult ‘able’ mother, with flaws and all. This deliberate act endeavours to re-shape the “heroic mother” stereotype.

A wistful form of humour also emerges when my vulnerability becomes apparent in a sequence where I break down and cry, feeling the burden in that moment of the first eleven years of Allycia’s life. Here Allycia as carer emerges as she uses our favourite toy to interrupt my crying, succeeding in turning my tears into a gentle smile. Her maturity and ability to connect with my sadness and the need to make me feel better are apparent and serve to challenge the status of intellectual impairment as burden. This sequence also served to help me laugh at myself in quite a different way after spending many hours confronted with the many faces that are mine during the editing process.

I experienced a great deal of discomfort in front of the camera due to feelings of self-consciousness and being on display. That discomfort paled into insignificance when I then had to watch myself on the monitor and triggered a parallel journey alongside the making of the film as I continued to view myself over time. Those images showing my distress, my face contorted with tears as I struggled to maintain control made me cry for quite a while afterwards. I felt a strange empathy for myself – as if viewing someone else’s pain although it was mine, simultaneously the same and other. Chris Sarra’s “notion of a **common core otherness** as constituting the essence of human being” is one that resonates closely with these aspects. Sarra reinterprets Bhaskar (5) arguing that “we should regard the **same** as a tiny ripple on the sea of **otherness**”, enabling us “to enshrine the right to be other” capturing “something of the wonder and strangeness of being” (5).

Over time I have become used to seeing these images and have laughed at myself. I believe becoming accustomed to seeing myself, aging as I have during these years, has been a useful process. I have become “more” comfortable with seeing that face, my face in another time. In essence I have been required to sit with my own vulnerabilities and have gained a deeper acceptance of my own fragility and in a sense, my own mortality. This idea of becoming “used to”, and more accepting of the images I was previously uncomfortable with has given me a renewed hope for our community in particular, the disability community in general. My experience I believe indicates the potential for us, as we become more visible, to be accepted in our difference. Critical to this is the need for us to be seen in the fullness of human experience, including our capacity to experience laughter and love and the delight these experiences bring to our lives and those around us.

These experiences are captured exquisitely when Allycia sees her newfound chromosome 18 friends, Martin and Kathryn kissing one another. She reacts in much the same way I expect other little girls might in a similar situation. She is simultaneously “grossed out” and intrigued, much to our delight. It is a lovely spontaneous moment that says much in the space of a minute about Martin and Kathryn, and about Allycia’s and my relationship. For me there is a beauty, there is honesty and there is transparency.

Able to Love

My desire for this film is similar to Garland Thomson's desire for her writing to "provide access to some elements of my community to both disabled and non disabled audiences alike" (122). I felt part of the key to making the film "work" was ensuring it remained accessible to as wide an audience as possible and began with a naive optimism that the film could defy stereotypical story lines. I discovered this accessibility I desired was reliant upon the traditions of storytelling; language, the construction of character and the telling of a journey demanded an engagement in ways we collectively identify and understand (Campbell).

I found our lives at times, became stereotypical. I had moments of feeling like a victim; Allycia as a dancer could well be perceived as a "supercrip" and the very act of making a film about my daughter could be viewed as a heroic one. The process resulted in my surrendering to working within a framework that relies upon, all too often, character construction that is stereotypical. I felt despondent many times upon realising the emergence of these in the work, but held onto the belief that something new could be shown by exposing "two narrative currents which are seldom included in the usual stories we tell about disability: sexuality and community" (Garland Thompson 114).

The take on sexuality is a gentle one, concerned with emerging ideologies surrounding sexuality in our community. This is a new phenomenon in terms of the "place" of sexuality and intimacy within our community. One of our parents featured in the film makes this clear when he explains that the community is watching a new romance blossom "with interest" (18q) and that this is a new experience for us as a whole. In focussing on sexuality, my intention is to provoke discussion about perceptions surrounding people categorised as intellectually impaired and their capacity to love and build intimate relationships and the possibilities this presents for the chromosome 18 community.

The theme of community features significantly in the film as audiences become privy to conferences attended by, in one instance, 300 people. My intention here is to "make our mark". There has been no significant filmic presence of Chromosome 18. The condition is rare, but when those affected by it are gathered together, a significantly "bigger picture" of it is presented where previously there was none. The community is a significant support network for families and is concerned with becoming empowered by knowledge, care and advocacy. The transcendence of global and cultural boundaries becomes apparent in the film as these differences become diminished in light of our greater need to connect with each others' experiences in life as, or with, people born with genetic difference. The film highlights the supportive, educated and joyful "shape" of our community.

In presenting our community I hope too that western society's preoccupation with normativity and ableism (Goggin) is effectively challenged. In presenting a version of life that "destabilises the system and points up its inadequacy as a model of existential relations", I am also demonstrating what Shildrick calls "unreflected excess, that which is other than the same" (105).

The most significant shift for me has been to refigure my ideas about Allycia as an adult. When I was given her medical prognosis I believed she would be my responsibility for the rest of my life. I did not hold a lot of hope for the future and could not have possibly entertained the idea that she may live independently or heaven forbid, she may enter into an intimate adult relationship; such was my experience with the physically and intellectually impaired. Thankfully I have progressed.

This progression has been, in part, due to attending a Chromosome 18 conference in Boston in 2007 where we met Kathryn and Martin, a young couple in the early stages of building a relationship. This is a new phenomenon in our community. Kathryn and Martin were born with chromosome 18 deletions. Meeting them and their families has signalled new possibilities for our children and their opportunities and their right to explore intimate adult relationships. Their relationship has given me confidence to proceed with an open mind regarding Allycia's adulthood and sexuality.

Conclusion

The very act of making the film was one that would inevitably render me vulnerable. Placing myself before the camera has given me a new perspective on vulnerability as a state that simultaneously disempowers and empowers me. I could argue this process has given me a better understanding of Allycia's place in the world, but to do this is to deny our differences. Instead I believe the experience has given me a renewed perspective in embracing our differences and has also enabled me to see how much we are alike.

My understanding of myself as both "able" and "othered", and the ensuing recognition of, and encounter with, my vulnerable self have in some measure, come as a result of being continually confronted with images of myself in the editing process. But more than this, reflecting upon the years since Allycia's birth I have come to a more intimate understanding and acceptance of myself as a consequence of knowing Allycia. Whereas my experience has been a matter of will, Allycia's contribution is in the fact that she simply is.

These experiences have given me renewed hope of acceptance of people of difference - that over time we as a society may become *used to seeing the different face* and the different behaviours that often accompany the experience of people living with genetic difference.

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