Ethics of Re-membering and Remembering: Considering Disability and Biotechnology

Jayne Clapton

Centre for Work, Leisure and Community Research

Griffith University

Abstract

Encompassed within forecasts offered by proponents of biotechnology about cures and control of disease and disability, are also predictions of an enhanced society. However, if the citizenship of our society is to be ‘re-membered’ in the future with processes of elimination being employed on some potential lives deemed not worth living, deep ethical scrutiny is required.

Hence, this discussion contends that when considering ethical decisions impacting upon the membership of future societies, there also exists an imperative to seek insight and wisdom by looking to past actions. The experiences and narratives of many people with disability and their families attest to some of these past actions whereby agendas of elimination have been imposed by practices founded upon both moral and socio-political exclusion.

When considering ‘re-membering’ in this context, a deliberation upon the imperative to remember will utilise the proximal text of a conference venue to contend that ethical reflection in this biotechnological era must embrace a process of anamnesis of past practices, rather than the more common approach of amnesia.

Keywords: Ethics, disability, biotechnology, memory.

Introduction

Whenever science and technology have intersected throughout the history of humanity, human societies have also undergone challenge, crisis and change in terms of structure, membership and participation. Important questions always emerge when such intersections take place. These include: How is the membership of the society changed? Who are in and who are out? Who have knowledge and power and who do not? Who are the decision-makers and who are the silenced? Who are designated as typical citizens and who as atypical? Which lives flourish and who are denied opportunities?

For instance, in this contemporary era, societies are being presented with the promises and prosperity of various biotechnological advances, particularly those offered in the fields of biomolecular science and genetic technologies. Ethical reflection about how such technologies provide the capacity to redefine citizenship along with the measure of their humaneness for all persons is continually being deliberated upon. The goal of enhancing societies without causing harm to the members, or potential members, must be of prime ethical consideration.

Such ethical consideration was the topic of discussion at an international conference held in Ipswich, Queensland, Australia, in July 2002. At this event, constituent issues of biotechnology, the new media and citizenship were discussed by the conference participants. As part of this process, participants were also invited to consider possible ‘sites of contestation’ of the dominant processes for ethical scrutiny that are most often presented in this context. One ‘site of contestation’ was identified...
to explore the impact of various contemporary biotechnologies on people with disability. This site is particularly significant when consideration is given to historical accounts of the impact of technological advances in relation to claims of cures and control of disease and disability.

This discussion, which is adapted from a paper presented at the conference, contends that when pondering upon how the citizenship of our society may be ‘re-membered’ in the future, as a consequence of biotechnology, ethical considerations that embrace the histories of people with disability become critical. By exploring narrative accounts of experiences of such people as recorded by family members, historical incidents where some ways of being human have been preferred to others are highlighted; and the often presumed foundations on which contemporary biotechnological practices are founded can be challenged.

Various steps are undertaken within the discussion. Why it is important ‘to remember’ is explored in a context of potential ‘re-membering’. The particularities of the context as experienced by some people with disability are presented against the theoretical explanations of the need to remember. Links between acts of re-membering and remembering in this biotechnological era are made when certain histories are highlighted. The ethical implications of such explorations are then discussed, suggesting that contemporary practitioners become more aware that ethical deliberations should be performed in a context of anamnesis - the act of remembering or recollecting, rather than amnesia - the act of not-remembering.

Why Remember?

Two reasons can be identified for why the conference should have considered the interaction between ethics, biotechnology and disability as a ‘site of contestation’.

Firstly, for people with disability, ethical implications have often left a legacy of not just moral exclusion, but of moral betrayal. In ethical deliberations within post-Enlightenment, industrialised Western societies, a particular type of citizen is seemingly more morally privileged than other types. When ethical deliberations depend upon the qualities of reason, autonomy and independence, those deemed without these qualities are continuously at risk of being pushed to the margins and beyond. Presumptions of both diminished personhood and indeed questionable humanity therefore conjointly embrace the tendency both to disqualify such beings from moral agency and to render their claims to moral membership and protection as somewhat irrelevant (Clapton, 2000, 1999).

The second reason was provided by the physical site of the conference venue. The Ipswich Campus of Queensland University presents as a contemporary campus of a modern university whereby the aesthetics of new buildings fuse with the heritage architecture of a time gone by when the site was used for other purposes. For over 100 years, such a purpose was that of being a large institution for both people with psychiatric disability and those with intellectual disability. The physical site represented, then, a proximal ‘text’ of an historical account of technologies of cure and control in relation to people with disability.

It seems apparent that in order to consider predictions about future humanity as proposed by biotechnological advances, there is an ethical imperative to seek insight and wisdom by looking to the past. In doing this, we are challenged to reflect upon why ethical agendas about the future should not be propelled from a position of amnesia of past events, but rather from anamnesis.

French philosopher, Paul Ricoeur (1999, p.5) states that remembering is a kind of action linked to exercising memory not just with words, but also with our minds. Furthermore, he describes three levels of practical applications of evoking memories for ethical significance: the pathological-therapeutic level, the pragmatic level, and the ethical-political level (Ricoeur, 1999, pp.6-7). Whilst the pathological-therapeutic level explores the wounds and scars of memory, along with notions of mourning and melancholia linked to the work of memory, it is the second and third levels that are pertinent to this discussion.

Ricoeur (1999, pp.7-9) describes how the pragmatic level represents the praxis of memory. It is this level in which problems of identity are explored. Whether personal or collective, the identity question of ‘who am I’, rather than the attributed ‘what am I?’ or ‘what are you?’ is constituted both by interactions with others and experiences of the self in time. He proposes that such identities are thus articulated through narrative, and represent a rich source of ethical insight. The
significance of the narratives becomes apparent not just in the expression of life experiences of the past, but also in the relevance for the future. It is the relationship between such experiences and ethical principles such as justice, beneficence and non-maleficence that are enlightening. Inasmuch as what is told or untold, what plot devices are used or not used, and what exemplars of events are discussed or not discussed, narratives are thus constituted and a subsequent form of ethical reflection becomes available.

Ricoeur (1999, pp.9-11) declares that in remembering, we are not only showing deep concern for the past, but are also being bound to transmit that past to future generations. Therefore, the ethical-political level of the application of memory considers whether there is, in fact, a ‘duty to remember’. In a context where history tends to celebrate victors and privilege the accounts of the powerful, Ricoeur (1999, p.11) contends that there is a duty to remember to keep alive the memory of suffering.

Through the use of narrative, the context of re-membering in this biotechnological era, presents a critical ethical opportunity. In fact, according to Saul (2001, p.215), not to remember will only create a vacuum in which propaganda and ideology of dominant agendas thrive. If the voices of those who have previously suffered at the hands of dominant proponents remain silent and their narratives are never sought, the expression of the identity question ‘who am I?’ is foreclosed. Such vulnerable people are constantly at risk of only being determined and referred to by the powerful in the objectified terms of ‘what are they?’ Nelson’s (2001) description of this phenomenon offers an important insight for the moral implications.

Identities mark certain people as candidates for certain treatments, and within abusive group relations these treatments are seldom benign. The connection between identity and agency poses a serious problem when the members of a particular social group are compelled by the forces circulating in an abusive power system to bear the morally degrading identities required by that system. (Nelson, 2001, p.xii)

A sustained suppression through not remembering also has an important moral effect. It prevents the opportunity for counterstories to be offered by such vulnerable identities in order to both subvert master narratives of control and to offer deeper ethical insight for the future (Nelson, 2001, pp.69ff). Hence, the ethical relationship between biotechnology and disability must encompass not only the scientific capacities to re-member, but also the narratives of people with disability themselves or of their families, advocates / carers as positive counterstories to the memories of past atrocities.

Re-membering and remembering

Utilising a broad range of technologies and possibilities, biotechnology promises to open up many of the unsolved medical ‘problems’ facing humanity. Paradoxically, though, such a pursuit is predominantly undertaken by a reductive project of modern biology, supported by strongly reductionist and analytical philosophical programs that have several implications for modern life sciences and humanistic relations (Sloan, 2000, p.9). According to Sloan (2000, p.xxiii), biotechnology poses questions about the nature of the human person, about the moral limitations on the technological manipulation of life, and about the definition of individual and social goods. If understandings of humanity are thus defined and causally determined within biotechnological contexts by micro parts, rather than expansive metaphysics, an ongoing ethical challenge remains. To what extent, then, are identity questions of ‘who we are’, rather than merely ‘what we are’ intrinsic to ethical discussions?

Assumptions of what it means to be human, or more pertinently perhaps, what constitutes the right way of being human are also implicit within such contexts. Individuals, or potential individuals, who fall into a biologically determined category of ‘not-right’ are at risk of their human membership being denied; and their personhood, or potential personhood, being negated. In other words, in such a biologically and philosophically determined reductionist context, the anomalous Other to the prototypical understanding of being human is at risk of elimination (Clapton, 1999). They are the negative, the bad, the not-desired, the harmful and the hunted in a context signified by enhancement, doing good and victory. With profound similarities to historical processes of colonisation (Clapton, in press A; Sibley, 1995), an agenda of choice and control becomes driven by an imperialist quest to conquer the unknown and overcome inferiority or imperfection (Dreger, 2000, pp.159ff). New technologies involving genetic testing, screening and diagnosis, advanced Assisted Reproductive Technologies, and improved detection and intervention procedures now impact upon which ‘humans’ will
constitute the membership of contemporary and future societies, and which humans will be denied life on the basis of being deemed a life not worth living.

People with disability become enmeshed in a web of constructions overseen by powerful disciplines such as science, medicine, law, philosophy and politics. Their status is viewed as representative of inferior or flawed humanity, but their presence is nonetheless respected. Proponents of biotechnology do not promote the elimination of living people with disability. Instead though, how such people’s lives are interpreted, does inform choices made in relation to procreative choices, foetal diagnosis and other situations involving imperilled or ‘needy’ humans.

There is no denying that advances in science and medicine have had many positive effects for the well being of humanity, whether such humans have disability or not. Biotechnological advances are thus promoted not so much in a context of control, but rather of care. Choices about which humans should live are not overtly made on the basis of elimination of inferiority, but rather within concerns of care and compassion towards the relief of suffering and burden. If people with disability are perceived as dependent, useless, harm-causing and non-productive by dominant moral subjects, then an ethical imperative of biotechnological practitioners to relieve or prevent the tragedy of their presence is seemingly justified. Consequently, if such practices also result in acts of elimination, these can be merely defended by a notion of ‘double effect’ – an effect by which the salvific intention also has political consequences of sustaining a particular social order which privileges superiority. These constructions, which constitute both a personal tragedy view of disability along with socio-political effects resulting in exclusion and oppression, are well documented in contemporary disability studies literature (see for example, Barnes and Mercer, 2003; Barnes, Oliver and Barton, 2002).

It is not surprising that historical links to the promotion of personal tragedy approaches continue to underpin contemporary biotechnological practices. Consequently, the capacity to determine which potential humans should be given life, is also often situated within the realm of medical ethics, and comfortably fits within these approaches (Clapton, in press B).

The ethical tenets associated with this ‘tragedy’ context, however, are becoming increasingly debated. Disability rights activists and other writers argue that biotechnology allows for discriminatory choices made against people with disability, and that such choices have their foundations in eugenic practices (see for example, Rowland, 2001; Wolbring, 2001; Kitcher, 2000; Vehmas, 1999; Shakespeare, 1998; and Hubbard, 1997).

Whilst ignoring the theoretical embeddedness of their stance, opponents of this view powerfully respond that any talk of active discrimination and eugenics within biotechnological practices is unfounded. Instead, they argue that the procreative choices of parents to not have a child with a disability should be respected (see for example, Gillon, 2001; Gillott, 2001; Harris, 2001, 2000 and 1993). Other writers recognise that some choices may indeed be eugenic, but again they are only made within the domain of personal choice, and not because of notions of political force, coercion, compulsion or threat towards particular populations (Caplan, 2000, pp.218-222). Savulescu (2002, np.) does concede, though, that when testing and termination are the only choices presented in pregnancies where Down Syndrome is detected, for instance, unjustifiable eugenics and discrimination does take place.

Koch (2001, np.), himself a person with a disability, suggests that in order to consider such deep ethical debates which perceive disability as inherently harmful and negative, ethicists, scientists and medical practitioners must consider insider voices and narratives of those who can relate the ‘experience’ of disability, rather than ethical deliberations being made on the basis of biological determinism alone. However, this approach does not readily fit with the dominant ethics employed in such contexts. Practices of care and control, embedded in both duty-based and utilitarian ethics (Vehmas, 1999; Sobsey, 1994), are easily linked to a view of people with disability as objects of science and medicine, and as targets of ethical action which require amelioration, prevention or cure.

Arguably, though, what is missed in the contemporary discussions of biotechnology, disability and ethics, is not whether contemporary and future practices are eugenic, but rather what constitutes past patterns of the experiences of people with disability with practices of care and control. The suspicion that is evoked from these experiences is pertinent and is particularly relevant when considering past experiences of people with intellectual and/or psychiatric disability. Past
(and present) practices of care and control have not only denied a sense of belonging for people with disability within society, but they have also concealed the telling of their narratives. In a context where individuals’ intellectual capacities may already constrain the possibilities of narratives, suspicions increase when narratives that can be told are not only ignored or not sought, but also when the experiences within the narratives are depictions of profound exclusion, violence and abuse (Clapton, 2000, 1999).

In a biotechnological era of re-membering the future, the imperative to remember past practices towards people with disability is apparent. When these ascribed anomalous Others have suffered at the hands of privileged practices and ideologies of dominant disciplines, we also have a duty to remember so that their experiences will not be forgotten when similar patterns present themselves before humanity.

**Remembering the Site**

Saul (2001, p.247) states, ‘History is the story of memory sorting itself out. Events and people are retained or dropped’. Therefore, it seems, the integrity of the history is located in the direct relationship between the tellers, what is presented, and what has been deemed important to present. The proximal ‘text’ of the conference venue, the Ipswich Campus of the University of Queensland, presents an exemplary context for remembering. However, remembering needs to account for three presenting histories: the recorded history, the analysed history and the experiential history. The use of narratives provides the opportunities for painful stories concerning people with disability to reflect how hegemonic interpretations of the ethical principles of autonomy, justice, beneficence and non-maleficence have not only affected their lives, but have sustained their vulnerability, particularly in regard to societal membership.

**The Recorded History**

‘The past’ of this text is presented in the *UQ Ipswich Campus Guide* (received 2002) as:

The UQ Ipswich Campus stands on a site once occupied by the Sandy Gallop Asylum, a branch of the Goodna Asylum, which began operations in 1878, housing 50 mentally ill patients. Sandy Gallop can be described as ‘the most complete example of an asylum in Queensland based on the principles of ‘moral treatment’.

Moral treatment emphasised a pleasant environment for patients, and at Sandy Gallop included employment and recreation areas, well-designed buildings, gardens and sweeping views of the countryside. (To preserve these views, the asylum employed sunken fences known as ‘ha-ha’s’, once common on English estates.)

In 1968, the site was renamed the ‘Challinor Centre’ after Dr Henry Challinor, a prominent local doctor and Queensland Parliamentarian of the mid-19th century. Reflecting changing practices in the care of people with intellectual disabilities, the Challinor Centre operated until August 1998, when the Centre was closed and construction of stage one of UQ Ipswich began.

The brochure refers to practices by which people with mental illness, psychiatric disability and intellectual disability were congregated together in custodial care in Queensland up until the late-twentieth century. Until the institution closed in 1998, there were many twists and turns in its history. As recorded by McRobert (1997), the notion of a complete institution was a facility that not only contained ‘patient’ and staff residential wings, but was also self-sufficient in all auxiliary aspects. For instance, the production and preparation of food, the doing of laundry, the maintenance of the buildings, the venues for recreation – including a cinema – the inclusion of a surgical building and operating theatres, as well as the presence of a mortuary and post-mortem facilities were all located within the site. In other words, all provisions were attained within the confines of the institution.

**The Analysed History**

In social terms, post-Reformation and newly industrialising societies became focused on productivity and profitability, underpinned by the forces of developing capitalism and the Protestant Work Ethic. In the second half of the eighteenth century the changing structure of the English economy underpinned structural changes in relationships of social order, such as the transition from master-servant, to employer-employee – relationships now dominated by rank, order, and class (Scull, 1993, p.31). People with disability became a ‘class’ requiring physical removal from the ‘able-bodied’ norms of mainstream society. The ‘institution’ or ‘asylum’, involving the State, evolved as a place with a dual purpose: (a) where people with disability could be placed so that family members could meet workers’ obligations; and (b) a place
where people with disability could be skilled to become productive members of society (Funk, 1987).

The history of the Challinor Centre refers to the influence of moral treatment and also to the work of its American proponents, Dorethea Dix and Samuel Gridley Howe who promoted a view of the asylum as a place of refuge. However, being established as a 'lunatic asylum' also locates it within a particular historical context. The 'lunatic asylum' was thus defined as both an institution for the support, safekeeping, cure or education of those incapable of caring for themselves such as people with mental illnesses or disabilities; and as benevolent because it supported people with insufficient income (McRobert, 1997, p.5).

Sandy Gallop was opened at a time which coincided with the impact of legislation passed to restructure the English and Welsh 'mad-business' in mid-19th century Britain. This shift to a formalised, medicalised context also saw the ascendancy of the profession of the so-called 'mad-doctors' (Philo, 1987, p.398). Therefore emerging practices of diagnosing, prognosing, categorising and pathologising those with mental illness and intellectual disability within asylums were situated in a professional context in which status and recognition were being sought. For instance, Philo (1987, p.399) notes that in the first forty issues of the Asylum Journal established in the mid-19th century by the authority of the Association of Medical Officers of Asylums and Hospitals of the Insane, the profession was seeking to establish its special expertise within the public arena. In comparison to previous practices offered by lay people who had previously been responsible for 'institutionalised lunatics', this new breed of professionals broadcast their self-proclaimed, salvific status:

'Oh what a holy, honourable and sacred occupation is that which we all have the privilege to be engaged: the angels of heaven might well envy us the ennobling and exalting pleasures incidental to our mission of love and charity.' (Winslow, 1858; cited in Philo, 1987, p.400)

'The physician is now the responsible guardian of the lunatic and must ever remain so ... insanity lies strictly within the domain of medical inquiry.' (Anon, 1853; cited in Philo, 1987, p.400)

The practices that developed in these asylums around notions of care and control towards anomalous Others, became embedded in a medico-moral discourse which represented 'medico-moral treatments'. These had some particular characteristics, which were not only clinical, but also physical and geographical; and which required spatial separation. Philo (1987, p.404) describes how there was a prevailing view in this Asylum era 'that the mentally distressed mind could only be cured by freeing it from the city and the factory, and by then giving it the benefits of a more 'natural' tranquil rural setting'.

Sustaining the supposedly beneficent telos of institutional 'care', however, became an enduring tension. The intention to skill people to be productive and returned to society could not only be unrealised in many situations, but also proved to have a limited vision. The institutionalisation trend occurred contemporaneously with the beginning of the modern era, with an increasing emphasis on scientism and social Darwinism, and an ongoing categorisation and classification of different humans. Social Darwinism would have a profound effect, not only for Darwin's notion of the 'evolutionary advantage of the fittest', but also for providing the foundation by which his cousin, Francis Galton, would develop the practice of Eugenics, the implications of which are highlighted by Davis (1995).

Darwin's ideas serve to place disabled people along the wayside as evolutionary defectives to be surpassed by natural selection. So, eugenics became obsessed with the elimination of 'defectives,' a category which included the 'feeble-minded,' the deaf, the blind, the physically defective, and so on. (Davis, 1995, pp.30-31)

The advent of statistical science was another great influence that would have deadly results. The eugenics movement progressed as an application of the development of statistics and the construction of the Normal curve; and hence was linked to an ongoing construction of normalcy (see for example, Davis, 1995, Trent, 1994). This is a complex concept which shifted from understanding 'typical' humans from a physiological view to defining 'right' humans according to statistical and psychometric means. Along with the study of statistics, 'normalcy' became not only the construction of excellence, but, considering the underside, also the construction of mediocrity and deficiency (Davis, 1995).

Promoted by prominent physicians and scientists of the late
1800s, eugenics is the ‘pseudo-science’ that dealt ‘with the improvement (as by control of human mating) of the hereditary qualities of a race or breed’ (Sobsey, 1994, p.119). Whilst the Darwinian view of natural selection depended upon nature’s actions to eradicate, the eugenic view attempts to ‘defy nature’, in favour of actions by a ‘privileged class who exercises control over the rest of humanity’ by the use of technologies to manipulate nature (Sobsey, 1994, p.120). Once people recognised the power in statistically ranking human superiority, the idea of increasing intelligence of humans and decreasing birth defects became achievable (Davis, 1995, pp.29ff). These interests were underpinned by the use of the body metaphor in reflecting the state of the nation and national fitness. If individual citizens are not fit, then the national body will not be fit (Davis, 1995, p.36). For people with disability, physical institutions became a site of segregation to both house the ‘scientifically-determined’ inferior humans and to prevent procreation. Wendell highlights how in cultures supported by modern Western medicine, and which idealise the idea that the body can be objectified and controlled, ‘those who cannot control their bodies are seen as failures’ (Wendell, 1992, p. 72).

The history of institutionalised practices, therefore, is both complex and ambiguous. When anomalous Others have interacted with dominant societal practices of an era, they have been subjected to various representations of ‘care’ and ‘control’. When these practices also encompass practices of elimination and undesirability, they have been underpinned by dominating disciplines like medicine, science, politics and philosophy which have been controlling in their determination of what represents burden and non-productivity. Whatever the context, when anomalous Others are configured by these disciplines as dependent and suffering and in need of professional determination and intervention, this has also significantly sustained an inferior moral status being applied to such beings or potential beings (Clapton, 1999).

The Experiential History
Institutional practices progressed until late in the second half of the 20th century. Children born with different conditions were relinquished by many families and placed in institutional care on the advice of medical personnel who declared to parents that such children could not be cared for at home because of the burden of care. With no other forms of support available in the community, families not only reluctantly surrendered their role as primary caregivers, but also felt a complex set of emotions with the deep sense of loss of a loved one. This was indeed the experience of quite a number of families of Challinor residents.

Narratives of some of these families have been recorded by the Community Resource Unit (CRU) in Queensland. The tenet of the narratives can be summed up in the comments of one parent, ‘The institution was a horrible experience. Nobody should have to go through that’ (CRU, 2001, p.72).

Other themes that become apparent are: despair; denial; separation; powerlessness; pain; confusion; obscenity; violence; horror and control. It is useful to look at some examples.

Despair
Parent:
Parting with you when you were still a child was difficult for both of us. You fretted and so did I. Many times I thought my tears would never cease, especially when I saw other children laughing and playing. I have often wondered what your thoughts were. You have never said. I wonder if I shall ever know your side of your life-story. (CRU, 2001, p.49)

Denial
Family Member:
The Managers were defenders of the system. We had the feeling that their main concern was to ensure that things got covered up: The truth mustn’t come out. When complaints were made it was the workers who got counselled. The people who had suffered at their hands were left to cope with it by themselves. (CRU, 2001, p.70)

Separation
Mother:
I look back over the seven years in the institution for Lynette. Gone are those adolescent years. What was lacking was our participating role as parents. We should have been involved in her life. (CRU, 2001, p.65)

Powerlessness
Sister:
They even changed Renee’s name, although not deliberately, but it is an example of how they took control without consideration for the family. For almost forty
years Renee was known as ‘Reenie’ at Challinor. When we would ask about Renee, staff looked at us blankly until we also referred to Renee as ‘Reenie’. (CRU, 2001, p.75)

Pain
Mother:
My new baby was sick and I couldn’t cope. Mum and Pop said it was the hardest thing they ever had to do, to take Annie to the Centre and leave her there. Pop never got over it. Mum accepted it. Pop was working each day and I don’t think he realised how hard it was for me to manage. (CRU, 2001, p.35)

Confusion
Parent:
No one would ever tell me if Libby was ever going to get better. Doctors didn’t talk to you in those days and I didn’t know what questions to ask. I was so naïve. When Libby was three we took her to a specialist at the Mater Hospital. He suggested that we should put her away in a home. He said she would ruin our lives. He didn’t tell me why he thought that, he just said, ‘Look, you’ll be better off putting her into an institution’. When I think back I still feel very upset about those comments. (CRU, 2001, p.67)

Obscenity
Mother:
Accompanied by the social worker, Libby and I arrived at Challinor and were taken to Francis House. This was the worst area of all at Challinor. We went in through the side door and the first thing that hit me was the stench of urine in the cracked tiles. The beds were all lined up. I remember a huge nursing sister, so large she could hardly walk. She showed me the solarium where Libby would be during the day. It was absolutely gross. Lots of people were sitting around the walls, propped up, in their own urine. I saw a mop in the corner: I’ll never forget seeing someone pick up this stinking mop and mop up all the urine, but actually making it worse. There were faeces everywhere. Some people weren’t even wearing pants. (CRU, 2001, p.44)

Violence
Sister:
I heard a whack and a scream.... I knew it was someone being hit. I turned to my mother and said, ‘Do they do that to Timmy, Mum?’ She just stood there looking at me.
I remember the look on her face and the tears in her eyes. She didn’t know what to say to me. I will never know the pain and heartache my parents endured back then. (CRU, 2001, p.55)

Horror
Family members:
No words can really describe that place. It was so awful. It was a place of detention, a place of containment. It would shock even the most hardened person. (CRU, 2001, p.72)

The narratives all record an ambiguity experienced by families in recognising that the place offered both site of care and refuge as well as helplessness and entrapment. This form of ambiguous memory is recorded by a sister:
We were then escorted through smelly, noisy, dank wards, past people in cages or rolling around on concrete floors, to a room where Renee had been placed for our visit, and the room was then locked. Renee never smelt nice. There was strong smell of lots of Johnson’s baby powder, but always the lingering hint of urine and faeces, the stale smell of soap, the odour of neglected teeth... not the stuff of fond memories. (CRU, 2001, p.54)

Remembering the Ethics
As Saul (2001, p.257) states, ...
... [M]emory moves in cycles and circles and so overtakes us when least expected. We are then caught in the repercussions of our actions. Suddenly we recognize the parallels with past acts. We both remember and are powerless to use that remembrance. Only a circular or cyclical approach would allow us to act and remember at the same time.

In line with Ricoeur’s (1999, pp.9-11) notion of pragmatic memory, traumatic narratives exemplify the many forms of past atrocities. Such remembering is not only to respect and recognise key identity markers of individuals, but arguably, also the collective identity of humanity in terms of how we interact with an Other. When groups of people such as people with disability experience both moral and socio-political exclusion, Ricoeur’s (1999, pp.9-11) notion of ethical-political
memory is also pertinent. Physical sites representing practices of such exclusion are ethically informing in regard to contemporary actions.

Why should we remember these histories in this contemporary era? What relevance do they have in discussions about biotechnological practices?

On the whole, the memories within these narratives and histories are not ones of humane treatment. The narratives in particular, exemplify the dominant experiences of anomalous Others as prescribed by practitioners of powerful disciplines with a capacity to control destinies. People with disability, when confronted with agendas of elimination or separation underpinned by notions of undesirability and burden experience oppression, cruelty and societal exclusion. Arguably, then, if ethics is a discipline to understand good and bad, right and wrong, justice, beneficence and non-maleficence, then the failure to protect such vulnerable Others on the basis that they represent not right ways of being human must constitute moral betrayal.

If the presence of disability is constructed ethically as representing harm, threat and unhappiness within discourses of tragedy and catastrophe, utilitarian ethics thrive, and underpin practices of dominion and prevention (Clapton, in press B). When considering and ethically scrutinising the biotechnological agenda of remembering the future one must be insightful to parallel patterns within the past.

Contemporary biotechnological practices provide mechanisms seemingly to prevent anomalous Others being subjected to the presumed trauma of having a disability. If such potential suffering, as well as economic and care-giving burden, can be prevented by technologies of detection and eliminating intervention, then according to utilitarians such as Harris (2000), this represents a good moral action. Of particular significance is that Harris (2000, np) then goes further to claim that to knowingly fail to avail oneself of such possibilities would in fact be immoral.

In the 21st century, the view that it is morally right or good to prevent the life of a person deemed to potentially suffer, is problematic. It merely represents a now somewhat outdated view of disability as a personal problem or tragedy of an individual or a family. This discussion has indicated, though, that what people suffer is not so much linked to their particular diagnosed conditions, but rather to how ‘different’ humans treat each other. How humanity and society are shaped according to science, medicine, philosophy, politics and economics affects such interactions. The narratives of representative groups who are rendered vulnerable by such deliberations are ethically important.

Ethical deliberations in regard to biotechnological implications for contemporary and future citizenship, however, should not be constrained to only narratives of moral and social exclusion. Other narratives representing what Nelson (2001) refers to as ‘counterstories’ can also be found. There is a significant body of literature supporting positive experiences of families who have a member with disability (for example, see Kittay with Kittay, 2000; Stainton and Besser, 1998).

How the focus of ethics towards people with disability in this biotechnological era comprehends relational acceptance, mutuality and interdependence found within counterstories, will challenge the dominant moral assertions promoted by disciplinary ‘experts’. Burden, in the context of counterstories, is recognised not as that configured by judgments of individual limit or loss ascribed according to a diagnosis, but rather that which is due to the lack of opportunities, support and a sense of integral belonging as ‘offered’ by an excluding society (Dowling and Dolan 2001; Clapton, 1999; Kittay, 1999; Landsman, 1998).

It becomes apparent that powerful disciplines involved in contemporary biotechnological practices need to revise their moral standpoints on these matters to include the moral knowledge gleaned from counterstories. Hence, contemporary views and scholarship which critique the long established personal tragedy approaches about disability are more useful to inform public discussions than those that continue to perpetrate moral and social exclusion. Not to do so will see disability activists continue to cast the actors of these disciplines who can only understand disability in negative, deficit-focused ways, as villainous, and the opportunity for deep ethical reflection as prohibitive.

Conclusion: Remembering Before Re-membering

In conclusion, this discussion has indicated how our present society must attend to the ethical challenges that emerge when we engage with the pragmatic and ethical-political memories available.
Saul (2001, p.254) asks whether memory should have an object; and therefore whether the act of remembrance should provide access to that object? This discussion has also highlighted how the Ipswich Campus of the University of Queensland provides an object by which to remember some of the lived experience of people subjected to agendas of elimination, separation and undesirability. Accounts of practices of care and control reveal an ambiguous context. Rather than compassion and protection, such experiences reflect tragic notions of oppression, violence and exclusion. When ethics, as a discipline, deliberates upon the capacities for biotechnological manipulations to determine which humans can be members of society, ethical reflection will be constrained and moral and social exclusion perpetuated if such deliberations are based only on the 'presumed' tragedy of individual lives rather than the tragedies imposed by inadequate social supports. Hence, the tragic implications of inhumane practices towards vulnerable, anomalous Others must be remembered not only to continually remind us of past examples, but also to prevent ethical deliberations being based upon now somewhat outdated premises.

When affected groups do not have access to ethical decision making, when their voices are not sought or are denied, and when sites of practices are converted and sanitised for other purposes, we lose, through these amnesic practices, the moral importance of the pragmatic and ethical-political memories that they offer. It is hoped, then, that in this biotechnological era requiring ethical reflection, we, as a collective society, will have the moral insight that such a loss be remedied. When processes of anamnesis are enacted and counterstories of positive experiences of disability are embraced, disability as a 'site of contestation' could be ethically refigured and transformed.

Address for correspondence:
Jayne Clapton PhD
Centre for Work, Leisure and Community Research
Logan Campus, Griffith University
University Drive
Meadowbrook, Queensland 4131
Australia
J.Clapton@griffith.edu.au

References


 Harris, J. (2000). Is there a coherent social conception of disability? Journal of Medical Ethics, 26:2, pp.95-100. (Electronic version)


Note


Savulescu, J. (2002). Is there a ‘right not to be born’? Reproductive decision-making, options and the right to information. Journal of Medical Ethics, 28:2, pp.65-67. (Electronic version)


Winslow, F. (1858). President’s address at the annual meeting. Asylum Journal of Mental Science, 16.