

## Disability care as women's work

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### Abstract

Why is disability care a lifelong role and responsibility for some women? How does disability activism and feminism view the role of disability care? This paper starts with an overview of the limited disability and care data we have in New Zealand, and what can be interpreted from the statistics about the gendering of care. Reference is also made to the new controversial 'Funded Family Care' policy for paying family members for caring for a disabled family member, the recent pay equity win for low-paid aged-care workers, and the 'sleepovers' case. To understand the present and to look into the future it helps to know where we have been, so some illustrative examples of current and historical gendering of disability and care are provided including: past eugenic policies; the mid 20<sup>th</sup> century struggle by mothers of intellectually disabled children; and mother blaming in autism. This is followed by a consideration of some theoretical approaches in helping to understand the situation from feminist and disability perspectives including addressing issues of ableism and power. The paper concludes with suggestions to address the issues of low status and pay for disability care.

### Key words

*disability, gender, care, mothering, ableism, eugenics*

### Introduction

My experience in the disability sector is as a parent, friend, advocate and academic. I got into the area of disability (specifically autism) through mothering. I found that a great deal of advocacy was required for any access to education or community inclusion for my disabled child and became involved at many levels, including on the boards of schools and community organisations. In all these roles the same gendered themes arise. In New Zealand, as in many countries, disability care is overwhelmingly the role and job of women, either unpaid or poorly paid. It is a role that may be life-long, and one that requires ongoing vigilance and responsibility. A more sinister trope sometimes blames women, particularly mothers, for disability, particularly of their own child.

This paper starts with an overview of the limited disability and care data we have in New Zealand, and what can be interpreted from it about the gendering of care. Reference is made to the new and controversial 'Funded Family Care' policy for paying family members for caring for a disabled family member, and the recent pay equity win for aged-care workers. To understand the present and to look into the future, it helps to know where we have been, so some illustrative examples of current and historical gendering of disability and care are provided including: past eugenic policies, the mid-20th century struggle by mothers of intellectually disabled children, and mother blaming in autism. This is followed by a consideration of some theoretical approaches in helping to understand the situation from feminist and disability perspectives, finishing with suggestions to address the issues.

### Disability statistics and gender

New Zealand's limited disability statistics reveal gendered differences. The disability sector commonly refers to one in five or roughly 20% of the population as having a disabling impairment.

This is reflected in the title of a long-running Radio New Zealand programme on disability issues called 'One in Five' and data from Census-related disability surveys of 1996 and 2001 (Ministry of Health, 2004). The last Census for which we have disability data was 2006 which reported a 17% prevalence rate. It is possible that disability is underreported or the nature of impairment misunderstood or misinterpreted as Census questions rely largely on self-identification (or carers or family members reporting for those assessed as unable to complete their own forms), and language which confuses impairment and disability – both words which carry cultural and political assumptions. Statistics New Zealand's current definition is: 'a disability is an impairment that has a long-term [six months or longer], limiting effect on a person's ability to carry out day-to-day activities' (Statistics New Zealand, 28 June 2013). They provide further guidance that impairments that can be readily addressed by aids such as glasses for short sightedness, are not considered a disability for Census purposes. However, interpretation of disability is largely left up to the individual. Anecdotally, many respondents choose not to self-report disability because of negative associations or implications of dependence. Statistics from the Disability Survey currently being undertaken following the March 2013 Census will be available in 2014 and may provide a clearer picture.

However, the data available suggest that there are more disabled women than men in New Zealand and women are worse off in terms of indicators such as employment and income (Office for Disability Issues, 2007). A young disabled person is more likely to be male and cared for by his mother, while females with chronic conditions dominate the older age groups. However, these older women are usually cared for by low paid female workers, not from their own family. Women from one impairment group for which there are some data, those with intellectual disability (ID), have a life expectancy of almost 23 years less than women without ID (Ministry of Health, 2011). There is no doubt that disabled people include some of our poorest and most vulnerable New Zealand citizens.

### **Gendered politics of care, unpaid and paid**

Caring work for such a population is a complex subject and one with gender differences, whether the work is financially rewarded or not. Carers New Zealand is an umbrella group for various community care groups which advocates for unpaid carers, and provides the secretariat for the New Zealand Carers' Alliance, a peak body of disability organisations which incorporate caring concerns (as distinct from DPOs – Disabled People's Organisations – which do not have a care focus). Their website ([www.carers.net.nz/](http://www.carers.net.nz/)) provides statistics related to caring. They have ascertained from the available data that more than 420,000 New Zealanders (one in ten) are involved in unpaid caring over and above the usual caring of a parent for a child (and they also assert that everyone will either care for or require care sometime in their life). According to the 2006 Census there were a total of 155,205 unpaid male carers, and 264,126 unpaid female carers. These included people who helped someone who was ill or had an impairment from the same household, as well as those who lived somewhere else. Carers New Zealand research also reveals carers face tension in the workplace with employers and colleagues as a result of juggling work and care responsibilities.

Caring for a disabled child is often a lifetime occupation for a mother (and it is usually the mother), although one with low value and status. It is euphemistically referred to by government agencies as 'natural' (meaning unpaid) support. Several years ago family members (mothers and some fathers and siblings) took a case against government policy as operationalised by the Ministry of Health not to pay family members who lived at the same address as the disabled person, for their care work. For a decade the case to remunerate family members caring for disabled adults on the same basis as non-family care wound through our legal system. Speaking against

payment were some male disability activists who did not want family carers paid through fears of potential abuse of the disabled person at the hands of the family carer, although other activists spoke in favour of payment. The case was eventually won, and after two unsuccessful appeals the Ministry of Health decided to accept the decision, undertaking a public consultation process in 2012 (Ministry of Health, 2013a). Several months later the Government's response to the decision was announced as part of the May 2013 Budget. The Minister of Health announced that the court decision had forced his hand over what he saw as societal expectations of parental support for dependents. He said:

Our society expects parents to care for and support their dependent children ... But the Court of Appeal ruled that this 'social contract' does not extend to continuing to care for adult sons and daughters who have a life-long disability. (Ryall, 2013)

But the new policy would be limited to only a few family carers of people with complex needs between 18 and 65, excluding spouses, who would be able to apply for the minimum wage for up to 40 hours a week. Not only was caring more than a 40 hour per week job in most cases, in a sting in the tail, no judicial review of this policy would be allowed. This unexpected move to deny legal redress through the Bill of Rights Act saw the rare situation of disability issues attracting the interest of academic constitutional lawyers who joined the resulting outcry from the Human Rights Commission and disability advocacy groups (Geddis, 2013).

The details of 'Funded Family Care' released in September 2013 included long and detailed eligibility criteria and complex procedures required for operationalising the policy including the disabled person's need to understand employment law as payment would be made directly to them, and they would become the employer of the family member (Ministry of Health, 2013a). Mothers and probably sisters, as the main potential caregivers of disabled family members in these situations of complex care, were not trusted to provide limited and minimum wage paid care without extensive contractual obligations. Meanwhile Margaret Spencer, the mother of a 44 year old disabled son, who had pursued her own decade-long court case against the Ministry of Health for caregiving payment, won her battle for assessment for payment in October 2013 (Kidd, 2013).

Care of non-related disabled and older people as an employment occupation is also predominantly the (low) paid work of women. The year 2013 also saw an historic pay equity court victory for the occupation of caregiving. A Hutt Valley-based aged-care worker with many years' experience, Kristine Bartlett, earning just above the minimum wage, took her case against her employer, through her union, to the Employment Court in order to obtain comparable remuneration for caregiving with similar but male dominated jobs. They won (Cullen, 2013; New Zealand Employment Court, 2013). The judgment noted:

It is common ground that there is a preponderance of female workers in the aged care sector. In 2009 there were 33,000 workers in the sector, 92 per cent of whom were women (mainly older women)... The defendant employs 106 female and four male caregivers. They are all paid at caregiver rates, which are around \$13.75 to \$15.00 per hour. The minimum wage is currently set at \$13.75 per hour. (New Zealand Employment Court, 2013)

The process of reviewing and funding aged care work in the light of this judgement has started but those affected will need to remain vigilant as pay equity has a long and fraught political history. Scrapping the Pay Equity Unit in the Department of Labour was one of the actions of the newly elected 2008 National Government, as was overturning pay equity legislation by the incoming National Government in 1990 (Ministry of Business Innovation and Employment, 2013).

Another legal battle related to caring, which took a long time to wind through the courts, also illustrates the low value and status of care work. In February 2011 the Court of Appeal upheld

the case of disability support workers (many of whom are women on low wages) on overnight duty in residential care homes, to be paid the hourly minimum wage instead of a reduced rate for 'sleeping overnight'. The case was taken by the Service and Food Workers Union and the PSA on behalf of a worker employed by the IHC's IDEA Services. Later that year the law was changed to apply the payment to all such workers. However, implementation has been a slow process, not helped by the fragmented nature of such contracted work, and by July 2013 only 70 organisations had completed the legal processes with many workers still to receive back pay and other organisations yet to complete the legal process (Ministry of Health, 2013).

A complicating factor in acceptance of the need to pay women a decent wage for caring is a trope that blames women (particularly mothers) for the caring situation they find themselves in.

## **Blaming women for disability present and past**

### **Eugenics and its remnants**

As Margaret Spencer's story of care for her adult disabled son, above, illustrates, caring work and responsibilities can be lifelong. However, public attitudes sometimes including a blaming undercurrent, as a recent media example illustrates.

Alison Adams of Christchurch featured in the news in April 2013 (Campbell Live TV3, 11 April 2013, 12 April 2013; Carville, 2013). Malcolm and Nigel, her two autistic and intellectually impaired sons aged in their 50s, were looking for some temporary accommodation while their earthquake-damaged home was rebuilt. The stories in the *Press* and on television's *Campbell Live* gave a hint of Alison Adams' life to this point. She was left a single parent when her boys were little (although she has since remarried) and has advocated all their lives for her boys, first to keep them out of institutions and later for community support. But at 78 she was getting tired so asked the public for help via the media. Some accommodation options arose, but things did not go as planned and three months later this family was in the news again over problems with building consents for their rebuilt house. These were eventually resolved (Turner, 2013). Coverage like this family's story is rare in the media in that it is a realistic portrayal of disability and care rather than assuming the usual tropes of disability and disabled people as either heroic or tragic.

However, following the Adams story in April, media commentator Michael Laws gave his assessment of the situation. Referring to Mrs Adams and another family which was also having trouble finding suitable accommodation for disabled family members, he wrote:

In both ... cases, our answer seems to be to let them muddle on. And then to finance the next generation of disabled and damaged children. Even encourage them to breed. That isn't an answer. But maybe that's because we refuse to ask the proper question. Isn't it time for us to think about who can and should have children, and who should not? (Laws, 2013)

This was not the first time Laws had blamed disabled people for their fate. Following the September 2010 earthquake and the beating and jailing of an autistic man caught up in the aftermath, he criticised the man's physical characteristics and the mental health of his family including his mother (Laws, 2011). In making such claims Laws is drawing on a long history of eugenic-based public policy. In early 20th century public policy, in New Zealand and internationally, the language of science was used to promote two related approaches; lock away or otherwise exclude disabled people from society, while also teaching women (those at risk of breeding 'defectives') to be better mothers (Stace, 1998).

The beginning of the 20th century coincided with an increasing interest in the science of genetics and heredity. In New Zealand these ideas were taken up by both liberals and conserva-

tives who were concerned about the decreasing white middle class birth rate and consequent fears of losing their racial (and moral) supremacy. Theories and language linked intellectual impairment and some physical impairments like epilepsy to inferiority and moral degeneracy. Negative eugenisists sought to limit fertility by public policy while positive eugenisists supported interventionist policies to increase population 'fitness'.

In this context, Plunket was started in 1907 to train mothers to grow healthy little citizens and soldiers for the empire. Founder Truby King, who had a physical impairment, later became Inspector General of Health. He, his wife, and their supporters were positive eugenisists who believed that teaching mothers the strict rules of scientific mothering would increase the 'fitness' of the race. Committees of middle class women then took the ideology to the breeding populace.

King was our local manifestation of the scientific mothering trend, and part of the international tradition of male experts telling women how to parent and then blaming them if anything went wrong. The mothers themselves of course were never consulted. French-born nun Suzanne Aubert had personal experience of disability and was one of the few to speak out against eugenics. She founded her Home for Incurables in Whanganui in 1899 and, in 1907, opened her first Home of Compassion for all 'needy' or disabled adults or children in Wellington<sup>1</sup>.

But certain types of intellectual impairment continued to be linked with 'immorality'. So girls' and boys' homes and farm schools were founded mainly to keep the genders apart and prevent criminality, deviant behaviour or reproduction. A residential school for 'feeble-minded' girls, Salisbury, was opened in Richmond, near Nelson.

In 1925 a Committee of Inquiry into Mental Defectives and Sexual Offenders linked intellectual impairment with moral degeneracy and potential sexual offending, and sought to separate suspect parents and children. At-risk children could be taken off families and the short-lived Eugenics Board kept lists of 'defectives' (Triggs et al., 1925). The consequences are expressed in this 'mothers lament' naming the Acting Inspector General of Health, Dr Gray:

'Oh Mother, save me from Dr. Gray  
'Cause teacher says he's coming to-day  
And if I'm stupid he'll take me away.  
Oh, Mummie, save me from Dr. Gray!'

'I cannot save you, my little child.'  
His Mummie said and her eyes were wild.  
'You belong to the State, you're no more my child!  
But Oh, my darling don't stupid be  
Or he'll say we've tainted heredity.  
And must be eradicated – you and me!' (Robertson, 1989)

### **Mother activism and intellectual disability**

Mothers of children with intellectual impairment continue to face stigma into the 21st century as Margaret Spencer and Alison Adams illustrate. However, they would perhaps have fared worse if it was not for the activism of earlier mothers of disabled children, such as the writer of the above poem and the mid-century founders of the IHC.

For even the establishment of the welfare state in the late 1930s did not remove the stigma of disability care; the treatment of people with intellectual disability and their families providing a further illustration of disability care as women's work, fault or burden (depending on the commentary). The activist parents who founded the organisation called the Intellectually Handicapped Children's Parents' Association (now the IHC) in Wellington in 1949, had the foresight to keep good archival records, in particular the first secretary Margaret Anyon (IHC New Zealand, 1947-2003). Their children from childhood to adulthood were officially considered to require only support from their families (meaning the mother as primary caregiver).

They were usually excluded from schools and there were very few dedicated facilities. Margaret Anyon and her husband Hal teamed up with other parents to lobby for a school. They had been working with the local Member of Parliament and Prime Minister Peter Fraser, and the Department of Education had found them a site for their school in Oriental Parade. But in the November 1949 general election the Labour government was voted out. Meanwhile some of the residents of Oriental Bay started a petition against the school. The new Education Minister refused permission for the school and the parents had to start again. Eventually, after some temporary accommodation at the Basin reserve, they found a site in Newtown, which served for many decades as a school and occupation centre.

But nothing happened without considerable lobbying and hard work, mainly by the mothers of disabled children. They wanted education for their children, some good respite facilities, occupations and residential care for adults. They were astute lobbyists. The new Minister of Women and Children, Hilda Ross, was also the only female cabinet minister. The women invited her on a tour around Wellington visiting several mothers at home with their disabled children to educate her about the reality of life without government or community support. She became an ally, although largely ineffective when it mattered in the male political world.

The IHC parents petitioned the government for an enquiry into support for their children. They wanted a government-led committee with representation and input from the parents, particularly the mothers. They anticipated that the findings would be in favour of schools and the small community homes which were by then international best practice. However, the Government appointed a Consultative Committee under the chair of a clinician and the Vice Chancellor of Otago University, Dr Aitken. Not only were no parents on the committee, there were no women. After parent protests a female lecturer in social work was appointed. In spite of best practice evidence and parental advocacy turning against the big institutions, the 1953 report of the Committee, which became known as the Aitken Report after the chair, recommended that disabled and mentally ill people (including children) be housed in large ‘mental deficiency colonies’ containing several hundred people. So for the next three decades many parents put their disabled children in such institutions and some even kept their existence secret causing considerable pain to many (Milner, 2008; Spectrum Care Trust Board, 2010). It was not until 2006 that the last large institution closed. As with the current calls for payment for family carers, the IHC parents of earlier eras wanted to care for their children, but to be supported by the state with their caring responsibilities.

This keenness by the state and its agents, such as Aitken, to break up families and institutionalise children was also in contradiction of the ‘attachment’ theory popularised at that time by John Bowlby. He emphasised the importance of mothers and children bonding and of mothers as the suitable carers for children (Bowlby, 1950). Why then was it considered acceptable to send young children away to institutions? It is hard to go past the contemporary assumption that disabled children were not considered fully human and were not expected to live long. There are many anecdotal stories of mothers being told by clinicians and officials to forget about their disabled child, and families being unaware about their missing sibling, sometimes until decades later when they reappeared as a result of the deinstitutionalisation process (Smythe, 2004; Spectrum Care Trust Board, 2010).

### **Mother blaming in autism**

The history of autism also provides a rich area for analysis of gender and disability – care and fault. From the time of the naming of the condition by Leo Kanner in 1943, to Bettelheim’s ‘refrigerator mothers’ to today’s neoliberalism, blame for autism has mainly landed on mothers (Nadesan, 2005). This idea of mother blaming persisted for many decades.

The study of childhood and of children being more than just little adults developed in the early decades of the 20th century. Into this context came Austrian born, German-educated pioneer child psychiatrist, Leo Kanner who by the 1930s was working in Baltimore as the first ever specialist child psychiatrist. He observed children who had an 'aloneness' and used the word 'autism' for this new condition (Frith, 2008). Kanner studied a small group of children of well-educated middle-class parents, and although he realised there was something genetic in their condition, he initially blamed parents, particularly mothers, saying that parents kept their children 'neatly in a refrigerator that did not defrost'. Apparently he later regretted saying this as the idea was taken up with enthusiasm by Bruno Bettelheim, of the 'refrigerator mother' theory, in his 1967 book *The empty fortress: Infantile autism and the birth of the self* (Bettelheim, 1967; Severson, Aune, & Jodlowski, 2008). Bettelheim was a holocaust survivor who was freed from a concentration camp on Hitler's birthday in 1939 and then migrated to the US where he found employment as the Director of a residential institution for children with supposed mental illness at the University of Chicago. He suggested the apparently autistic children in his care suffered from 'extreme situations' similar to being in the holocaust but caused by maternal deprivation and advocated what he called 'milieu therapy', a psychoanalytic approach to reaching the inner child, which unfortunately 'will always, to some degree, mean a descent to one's own hell' (Severson, Aune, & Jodlowski, 2008, p. 71).

But rather than being regarded as eccentric unqualified therapist, Bettelheim developed a following among a mainstream audience as a writer and commentator. So when his book *The empty fortress* was published in 1967, it had a ready-made audience. The empty fortress's 'refrigerator mother' motif was a useful tool in that by blaming parents, particularly mothers, it challenged the authority and expertise of mothers. Some call this the 'autism conversion narrative' involving 'visionary therapists who rescued children from toxic parents and the hostile culture threatening sensitive young people in post-war America' (Severson, et al., 2008). However, Bettelheim's theories have since been shown to be false and some of his former child patients later reported emotional and physical abuse.

Yet the impact of these theories at the time were considerable. One of my research informants who started the Autistic Association of New Zealand (later Autism New Zealand) said it was almost impossible to fundraise for autism in the 1960s and 70s because you were seen as bad parents. She was very pleased when autism was shown to be genetic (Stace, 2011).

Mother blaming for autism is significant because mothers have been fighting it ever since. One of the ways many middle-class mothers have fought back against such views is by becoming experts on child development themselves – as their mothers and grandmothers had earlier done under the influence of the male child rearing 'experts' of their eras. Although mainstream science no longer blames mothers for autism, neoliberal ideas of individual responsibility still do. Mothers learn what is 'normal' and from surveillance of their children's development become alert to any supposed 'deviance': mothers anxiously observe their children and seek professional help as soon as their child falls behind some ideal (Nadesan, 2005). This professional help can take many forms, including therapies and medications with and without an evidence base, and can have considerable time and financial cost (Green et al., 2006).

## **The intersection of caring, disability, gender and feminism; some theoretical approaches**

So why are disabled people and their care so lowly valued? It could be because we fear disability. Feminist Jenny Morris noted this following her accident in 1983 which left her dependent on a wheelchair for getting around. 'I became someone whose physical condition others

feared' (Morris, 1991, p. 2). As a society we like to 'other' disabled people – inclusion is more of a challenge and much harder than exclusion because it means we, the non-disabled, have to change. As mentioned earlier, we have a long public policy tradition of portraying disabled people as less than fully human, which justifies putting them out of sight in institutions or residential schools to separate them from the non-disabled humans (Newell, 2005).

Disability policy theorist Dana Lee Baker (2011) has usefully divided the sometimes competing disability agendas into 'cause, care, cure and celebration'. Regarding 'care', she notes that in the past, 'Girls were taught of a fundamental connection between caregiving and womanhood, thereby rendering less feminine those who choose not to provide care and minimizing complaints by overwhelmed care providers' (2011, p 48). However, despite feminism fuelling changed expectations of roles for women these essentialist ideas remain entrenched, 'Women tend to still be the primary caregivers, at least within relationships involving the care of those with higher level needs, such as children and those with atypical functionalities resulting in disability' (ibid). So there is a tension for women between their rights to seek employment outside the home but also in the need to provide care for family members, which is reflected in the Carers New Zealand research cited earlier. One response is to bring the professionalisation of care (such as payment and regulation of employment conditions) into the family situation, which is one reason behind the family carers' legal case. However, even paid care, as discussed earlier, is poorly valued, regulated and remunerated.

Meanwhile, feminist disability activists are creating their own epistemologies of disability that challenge assumptions of disability as deficit and disabled people as less fully human, which flows into the lowly value of disability support and care. They are developing their own critiques of 'ableism', which, as with feminism, racism, and sexual orientation it is about who is defined by the majority as 'other'. Disability activist and academic Fiona Kumari Campbell (2009) argues that ableism projects a particular kind of self and body as essential to be fully human; one that is fit, active and healthy. Disability is thus cast as a diminished state of being human and should the opportunity present itself, be ameliorated, cured or eliminated. Under these circumstances persons with severe impairments often trigger responses such as fear, revulsion or confusion and assumptions that the disabled person's life must be terrible and not worth living.

Another challenge to the dominant narrative of disability as deficit was the development of what is known as the 'social model of disability'. The social model arose from the ferment of the 1960s when people were challenging the power of the ruling minority, in this case the able bodied patriarchy, and was developed by disabled people in Britain (Oliver, 2009). At the same time there was a challenge to academic positivist research methodology and the assumption that there was some objective truth to be found. In what is sometimes called the 'paradigm wars' (Denzin, 2012) academic disciplines such as women's studies, sociology and other social sciences developed research methodologies which respected and included the phenomenon of lived experience, and challenged traditional power relationships. The 'social model' placed the responsibility for the creation of 'disability' on exclusionary structures and attitudes of society. As the 2001 *New Zealand Disability Strategy* developed by disabled people, explains:

Disability is not something that people have. What people have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is a process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have (Ministry of Health, 2001. p. 1).

The social model has implications for disability care, seeing it as a societal obligation, not one just for individuals or individual families to bear. But this awareness is slow to be realised in government operational policy.

Some disabled feminists who also had caring responsibilities were thus uniquely qualified to critique both the disability movement and feminism. Jenny Morris (1991, 1998) mentioned above, is a British feminist who was disabled following an accident in 1983. Although she was pleased to find that disability activism at that time provided a political perspective (the emerging social model) to understand her new situation, she also found disability activism could be sexist and disabling - 'the disabled people's movement also tended to treat disabled women's particular experiences as invisible' (1998, p.1), and noted that as 'disabled women do not have the opportunity to set the research agenda or to carry out the research, so our experiences are inevitably defined for us' (ibid, p.5). She found instead that she was defined by society as having a 'double disadvantage' of being both disabled and female. But that conflicted with her feminist analysis of women not as passive victims as the 'double disadvantage' label implied, but of 'asserting resistance, of struggling against oppression' (ibid, p.5). However, she also found that some in the feminist movement were not welcoming of disabled women for similar reasons to those Baker (2012) later identified. Displaying their ableism, some feminists said women's disability issues were the province of the disability rights movement and not the women's movement. Some able-bodied women could only see disabled women as 'dependent' or even a burden to the aspirations of non-disabled women, so promoted residential care as a solution. They ignored the fact that disabled women also had family responsibilities including care for others. Disabling environments and attitudes meant some disabled mothers feared seeking assistance from professionals as their children might be taken away. As well as control over their own lives, Morris found that disabled women also needed to have 'choice and control over the assistance they need to fulfil their caring role within the private world of the family' (1998, p. 6). Poverty was also a significant issue for many disabled women which was often overlooked in feminist or disability discourses.

New Zealand women have played a more equal role in disability activism and discourses about disability care. An example is feminist, former journalist and later Human Rights Commissioner, Robyn Hunt who has been at the forefront of local activism for many decades<sup>2</sup>. New Zealand activists and Ruth Dyson, the first Minister for Disability Issues, were also heavily involved with the development of the United Nations Convention of the Rights of Persons with Disabilities, completed in 2006 and ratified by New Zealand in 2008. It is also firmly based in the social model of disability, and disability is self-identified. However, instead of 'disabled people' (meaning disabled by society) it uses the internationally more common 'people first' language of 'persons with disabilities'. Article 6 of the Convention specifically mentions disabled women:

States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. (United Nations, 2006)

Other factors which may explain the current situation of disability care as women's role are love, luck, expertise and power. In my research on autism I found two things that make a positive difference to people with autism: I called them 'love' and 'luck' (Stace, 2011). These are intangibles and hard to measure. Love means someone to be there, to accept unconditionally and to advocate for as long as it takes, which is often a lifetime – just like Alison Adams, and many other mothers of disabled children and adults. The other factor is luck in finding appropriate services and support when you need them. These roles are also likely to be filled by women. This was exemplified by the audience for 2012 Autism New Zealand conference, the attendance at which was overwhelmingly female. Although autism prevalence means about four times as many boys as girls are affected, it is women who provide the bulk of care (such as parenting and advocacy) and professional support.

Yet when you look at the links between status and pay, the autism experts (often the keynote speakers at such conferences) are usually men, or occasionally women with high academic status in clinical or educational disciplines. So the closer you get to a disabled person the lower status and the lower paid the work is, if paid at all, and these roles are gendered. The less time the 'expert' spends with the disabled person the more they are paid, while lived experience of disability is generally not valued at all by those in powerful positions. For example, the government's Welfare Working Group whose work had a big impact on disabled people who depend on welfare benefits, had no members with lived experience of disability (Stace & Sullivan, 2011). In this respect little has changed from the era of eugenic public policy when male experts told women how to be proper mothers. In families, parents may also have different ideas to the disabled person about what is best for them. These arguments were canvassed during the family care legal battles when some disability activists argued against paid family care as potentially abusive, and such distrust could be behind the empowering of the disabled person as employer in the new Funded Family Care policy. However, until public policy ensures quality, well paid, professional disability care is available to all who need it, the bulk of the role will remain with mothers, or lowly paid women workers, while well paid men will be considered the policy, clinical and political experts on disability.

### **Conclusions: How to better value the disability caring responsibilities of women and disability itself?**

The available data, supported by numerous examples, shows that disability care, both paid and unpaid, is predominantly the role of women. There are numerous reasons for this situation from essentialist ideas of femininity, to economic necessity, to ableist fears of disability itself. The work of disability care also presents philosophical and theoretical problems for both disability activism and feminism and raises questions about where disability care belongs, and whose responsibility it is.

Public attitudes can even reinforce an undercurrent of prejudice against disability, as occurred when the media publicised the story of an ordinary family of a mother and her two disabled adult sons seeking temporary accommodation in the aftermath of the Christchurch earthquakes. A commentator then saw it as a chance to criticise, and blamed families of disabled people, particularly mothers, for their situation, questioning the need for disabled people to exist. As examples given in this paper show, such thinking has been with us for over a century. It finds expression in an extreme individual/medical model of disability, fear of 'otherness', and ableist attitudes whereby defect not only lies with the individual and by extension the family, but threatens the rest of society. Mothers of intellectually disabled and autistic children fought it for many decades and many still do. Members of the population holding such historically entrenched views are active in the media and politics. Carers such as Alison Adams, and her sons, have to face them every day. Such attitudes also explain why disability expertise and status is given to those who may only rarely or never interact with disabled people, and why parents seeking adequate financial support for caring for their disabled adult family members are dismissed by government.

One way to tackle the entrenched prejudice against disabled people and their powerlessness and their carer displayed in the above examples is to borrow another of Baker's (2011) disability agenda items – 'celebration'. An approach focusing on celebration of disability and the diversity of humanity could create a society that is welcoming and inclusive of all people, as envisaged in the *New Zealand Disability Strategy*. An example of such an approach is Jen Birch's (Birch, 2003) autobiography *Congratulations! It's Asperger syndrome* which de-

scribes her life before and after diagnosis, and her reflections on the strengths of autism. Baker suggests that the politics of care and celebration can overlap and both connect to questions about identity. But she also warns against celebration becoming patronising. Person-centred approaches which give dignity and control to those being cared for are required. Those most affected are then rightly considered the experts.

Celebration of diversity and of our human interconnectedness is one way we can all challenge the ableism of those who seek to demean disability and disabled people. If disability, and the lived experience of disability, can be celebrated socially and politically, so will the work of caring increase in status and be valued, inside and outside the home. However, to get to this point we individually and as society need to reflect on our own ableism, and tear down the barriers we build to acceptance and inclusion. Reasons for such attitudes may be as diverse as ignorance or fear of disability and disabled people, or entrenched philosophical views about what is and what is not appropriate work for women, and how the role of caring for others, paid or unpaid, fits into that philosophical framework.

In the meantime we need to use all the weapons available to build the intrinsic value of disability and recognise the full humanity of disabled people, and thus disability care, whether it is done by mothers, other family members or unrelated employees. These weapons include the power of the state, the legislature, the unions, the fourth estate and social media. The personal is, as ever, political.

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## Notes

- 1 The Aubert philosophy of non-judgemental caring for all people regardless of impairment is expressed by the 90 year old Home of Compassion resident, Sister Loyola, in the 2013 documentary, *Gardening with soul* (New Zealand on Screen, 2013).
- 2 Although she remains frustrated that even Women's Studies conferences need to be reminded to fully include disabled women (from Facebook discussions around the 2013 WSANZ conference).

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