

A **society** that highly values **lives** and continually enhances our **full participation**

The final report of the Welfare Working Group (WWG) (2011) was released at midday on Tuesday 22 February. Pre-publicity promised a shake-up of the welfare system. Within an hour the 6.3-magnitude Christchurch earthquake struck, and words like 'shake-up' and 'ground-breaking' took on new and terrifying meanings, while over the coming weeks understandings of 'welfare' changed. A few days earlier the prime minister had suggested that people used foodbanks because they made poor lifestyle choices (Trevett, 2011). Now people queued up for emergency financial assistance, as well as for the basic human needs of water, food and portable toilets. Electricity, water, housing, employment and education are still insecure for many Christchurch people. Those in the back rooms of the public service worked long hours over many weeks to support workers on the front line. In a mammoth but unreported task, dozens of disabled people were visited, and many temporarily or permanently relocated elsewhere around New Zealand.

The earthquake dominated the media for many weeks, distracting attention from the WWG report, which was relegated to corners of the blogosphere. But work on its implementation continued. What, then, are the implications of the report for the thousands of individuals and families coping with disability and welfare support?

Disability policy and the New Zealand Disability Strategy

It is generally estimated that one in five New Zealanders has a physical, intellectual, vision/hearing or neurological impairment or difference, mental health condition or learning disability, although only 17% identified themselves with the specific conditions listed in the last disability survey (Statistics New Zealand, 2007). Disabled adults are over-represented in statistics for poverty, lack educational qualifications, and many are on benefits (Ministry of Health, 2004).

Many in the disability sector hold suspicions and strong feelings about the work of the WWG, and to understand these it is important to consider New Zealand's current disability policy context and its history, and why language in the report such as the 'fit notes' (p.86) and 'reassessment processes' (p.70) causes alarm. Only a generation ago many disabled people were living

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in institutions or with their parents. The main employment option was sheltered workshops; a few may have been lucky enough to find unskilled jobs in manufacturing industries or the public sector. Life expectancy for most was low. But times have greatly changed. One consequence is that after many significant policy victories, New Zealand disabled people now expect engagement in policy initiatives which affect them. The international disability rights slogan 'nothing about us, without us' (Charlton, 1998) has been heard in the top levels of the New Zealand government, to the extent that disabled people worked in partnership with New Zealand government officials in New York on the drafting of the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

However, although the disability industry was represented on the WWG, neither disabled people nor disabled people's organisations (DPOs) were, and the inferred message for many in the sector was that it did not value their lives. The mission of the WWG was tackling 'welfare dependency', although this was couched in the more aspirational language of 'promoting better work outcomes for sole parents, sick people, disabled people and other people at risk of long-term benefit dependency' (WWG, 2011, p.1). An alliance of DPOs, Christian and other non-government organisations, social justice activists, academics and others soon formed Welfare Justice, the Alternative Welfare Working Group to provide a contrasting narrative of welfare. Welfare Justice ran several open forums around New Zealand to encourage input into the work of the official WWG and their alternative report which was published in December 2010 (Welfare Justice, 2010).

The title of this article comes from the first page of the 2001 *New Zealand Disability Strategy* (NZDS) (Ministry of Health, 2001), a policy document developed by disabled people and their organisations in partnership with government. The NZDS promotes the 'social model' of disability, whereby people have impairments but disability is understood as a process imposed by

the rest of society, producing 'disabled' people. Its introduction explains:

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the 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)

After hearing complaints of poor treatment, Parliament's social services select committee conducted an inquiry into the quality and care of disability service provision which reported late in 2008.

In this paradigm, a spinal cord injury is an impairment requiring a person to use a wheelchair to get around, but a lack of ramps creates disability. In the alternative, 'medical' or 'individual model' paradigm, the impaired individual is the inconvenient problem, whose life is often portrayed as tragic and their carers as heroic.¹

The NZDS has 15 sections, and, although it is not legally enforceable, government departments and agencies are required to measure against it in their annual reports. Particularly significant for this article are government objectives to provide opportunities in employment and economic development for disabled people (objective 4); foster leadership by disabled people (objective 5); foster an aware and responsive public service (objective 6); and create long-term support systems centred on the individual (objective 7) (www.odi.govt.nz).

The NZDS was the result of disability sector activism. Kingdon (1995) has written of the significance of policy 'entrepreneurship' and policy 'windows'. During the 1990s disability 'entrepreneurs' lobbied politicians, particularly through

the Labour and Alliance parties, on the need for new, social model-based disability policy. The election of the Labour-led government in November 1999 opened a window of opportunity. The results were several successes for disability activism, including the NZDS, the creation of a ministerial portfolio and an Office for Disability Issues within the Ministry of Social Development; significant policy development, such as the 2006 closure of Levin's Kimberley Centre, New Zealand's last psychopaedic institution; the end of sheltered workshops, and the right

of disabled people to the employment conditions enjoyed by non-disabled people with the repeal of the 1960 Disabled Persons' Employment Promotion Act; and the recognition in 2006 of New Zealand Sign as the country's third official language. One of the last acts of the Labour government was the 2008 ratification of the UNCRPD, following the passage of the Disability Act to ensure that New Zealand legislation was compliant with it. In 2007 New Zealand's record on disability was recognised with the Roosevelt international disability award (Dyson, 2007).

In spite of these high-level achievements, however, many services for disabled people remained inadequate. After hearing complaints of poor treatment, Parliament's social services select committee conducted an inquiry into the quality and care of disability service provision which reported late in 2008. The new, National-led government took note of many of the recommendations, and in 2010 signalled a 'new model' for supporting disabled people which would have a stronger focus on person-centred supports (Office of the Associate Minister

of Health, 2010). A programme of work is now being implemented through the Ministry of Health's Disability Support Services, including the establishment of a reference group comprised of disabled people and service providers.

Given their involvement in disability policy over the last decade, disabled people and their organisations now expect to be engaged in the design, process, implementation and evaluation of policies and programmes that affect them. Disabled people and their families have a great deal of valuable expertise and wisdom from their

Security Act, with its underpinning values of compassion and progressive taxation supporting a 'cradle to grave' welfare state. It is easy these days to underestimate the effect of this legislation. Until then New Zealand had largely depended on a charity model of disability welfare. The first disability pension was introduced in 1915 for miners with phthisis. Blind people were the first to get an impairment-specific pension, in the 1920s, following advocacy from returned soldiers (Tennant, 2007). This pension was not means tested, and welfare payments for people with vision

It is noted that independent specialist assessment is expensive and should be reserved for only the most complex cases, implying that fitness for work assessment will normally be carried out by approved medical doctors (WWW, 2011, p.70). The problem with this is that it individualises and medicalises disability, which is at odds with both the NZDS and the UNCRPD, both underpinned by the social model of disability, and to which the WWG appeals in its mantra that disabled people have a strong desire to be in paid work (WWG, 2011, pp.114, 113). Of course disabled people want 'to lead an ordinary life and make a contribution to society' (ibid.), but for the WWG the only way they can do this is through paid work.

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lived experience which can be well utilised in the disability policy process. After all, who better to improve a system than those who live with its effects every day?

The relevance of disability and welfare history to the WWG

As part of the WWG work a forum was held in Wellington in July 2010 at which several speakers were challenged to consider the perspectives of disabled people. The urgency of this challenge needs to be understood within the 20th-century context of eugenics-based policies targeting disabled people, grading their 'fitness', linking disability with inferiority and immorality, and of institutionalisation. In 1903 W.A. Chapple published *The Fertility of the Unfit*, in which he preached the sterilisation of the 'unfit', meaning, at that time, people with mental, moral and physical 'defects'. The WWG suggestion of contraception for single mothers receiving a benefit is alarming for its resonance to such attitudes. In 1911 the Mental Defectives Act classified groups of 'other' into idiots, imbeciles and feeble-minded to indicate whether a person had any potential for education or employment.

At the Wellington forum there were also many references to the 1938 Social

impairment are still the only category of disability benefit not to be means tested. However, other disabled people had to find work or rely on the generosity of family or charities.

In his book *The Quest for Security in New Zealand* government economist W.B. Sutch (Sutch, 1966) deplored the make work-schemes of the Depression and cited the example of a woman who pushed her husband in a wheelchair a considerable distance to report each day for relief work. An early response by the first Labour government to this kind of indignity was the 1936 creation of invalidity pensions, followed two years later by the more encompassing 1938 act which brought in means-tested invalid's and sickness benefits. The government's premise was that the state should be responsible for its citizens, and it rejected the idea that insurance be required before support would be given.² We suggest that work-for-the-dole programmes, or the 'jobseeker' label proposed by WWG, need to be carefully thought through so as not to reflect back to the indignity and human waste of the Depression relief schemes.

Under the WWG's recommendations all people on invalid's and sickness benefits would be reassessed and assigned a 'fit note' to signal their ability to work.

Changing definitions and mixing models

As already indicated, the final WWG report uses two contradictory concepts of 'disability'. On the one hand it continues to use medical model understandings which link disability and illness, and has general practitioners as gatekeepers (even though current medical training in disability and disablement is minimal). Key aspects of the report conflate sick and disabled people and the invalid's and sickness benefits (for example chapter 6: 'Support for sick people and disabled people with long-term needs' and recommendation 6: 'Work expectations for people who are sick or disabled') (WWG, 2011, pp.113, 21). On the other hand it uses the social model/ rights-based language of the NZDS and talks of the disabling nature of the welfare system, rights to work and participation, and acknowledges recipients' dislike of the invalidating term 'invalid's benefit'. This mixing of disability with illness and welfare with charity has long been problematic for disability activists, who asked for an independent Disability Commission in the recent social services select committee inquiry (Social Services Select Committee, 2008).³

Disability policy theorist Dana Baker has analysed this dilemma of contradictory understandings of 'disability' and notes that although 'modern disability policy is close to the constructivist end of the continuum, current policy tends to retain limited essentialist elements' (Baker, 2006, p.177). This means that

modern disability policy is about the social construction of disability (social model) but operations are based on fixing individual deficit (medical model). This explains the confusing situation operating in New Zealand: a rights-based policy orientation (NZDS) but a needs-based service delivery system (Jane has a right to a wheelchair versus Jane needs a wheelchair). The WWG report uses the language of the NZDS, but the 'benefit dependency' assumption reveals medical/individual-model thinking that disability is the problem, even the fault, of the individual. In this scenario an unmotivated individual is held back by their personal disability, which can be resolved if the individual becomes motivated. Gestures towards employment support are all that are required; but this picture ignores the reality that even in times of full employment disabled people still have a high rate of unemployment (WWG, 2011, pp.42-3). There is little recognition that society and its structures disable, that society needs to tackle its discriminatory attitudes and to recognise that people's lives are complex and that impairments plus poverty create extra barriers; little recognition that government must create jobs and provide incentives for employers to employ disabled people as well as improve access to education, training and transport. But the WWG report optimistically claims: 'The initiatives presented in this Report are expected to lead to increased employment of sick people and disabled people and therefore higher incomes' (p.176).

Paid work as a moral good

Underpinning this report is an assumption that paid 'work' is a moral good for individuals. Welfare is no longer to do with reciprocity from the state to create jobs or any sense of community well-being, values which created the welfare state. Welfare is now actively work-focused. People on the invalid's benefit are assumed to be able to work unless proved otherwise through 'a comprehensive assessment of their ability to work' and 'engagement through work-focused interviews, action plans and work-related activity' (WWG, 2011, p.68). The report values only work for money,

while ignoring the 'social capital' value of unpaid work such as caring for relatives, bringing up children and voluntary work. 'Civic contributors' is a suggestion raised (p.117), whereby welfare money would be channelled through non-profit organisations and unemployed people would negotiate contracts with these organisations for 'non-essential' duties. However, this would mean less money for the person than a direct benefit payment to them, as the organisation would take its cut. Would that organisation then be required to provide proper employment

pushing people 'off benefits and into low paid, insecure and health-damaging work is not a desirable option' (Welfare Justice, 2010, p.87). With respect to the invalid's benefit, two important consequences flow from the WWG's insistence that the only work which counts is paid work: first, it fails to acknowledge 'the fluctuating capacity, suitable work or understanding [of] the total impact of having more than one impairment, which is the experience of most disabled adults'; second, it overlooks the value of the 18.9 and 15.7 hours voluntary and unpaid work single

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conditions? The suggestion is also patronising as it assumes that the work volunteers do is 'non-essential', whereas much of the voluntary work beneficiaries do is vital not only to the functioning of many organisations but also to the New Zealand economy (Tennant et al., 2006).

We are told lack of work is bad for people's health whereas we would have thought that dealing with negative societal attitudes, navigating Work and Income, and coping with poverty were what was unhealthy for beneficiaries. Under a work-focused welfare regime there would be a general obligation on all beneficiaries to accept any reasonable job offer (WWG, 2011, p.73), the rationale behind this being that research shows that it is far healthier to be in work – even low paid work – than on a benefit, as this provides a stepping stone to better incomes (ibid., fn 57, p.73). In adopting this position the WWG rejects the evidence provided by the Alternative Welfare Working Group which shows that the quality of work matters: 'Insecure and poor quality employment is also associated with increased risks of poor physical and mental health'; and that

and partnered invalid's beneficiaries carry out each week respectively (WWG, 2010, pp.98, 90). If such people were forced into low-quality, low-paid work a significant opportunity cost would be incurred.

Other flawed assumptions in the WWG report are that the only work beneficiaries can aspire to is low-skilled, low-paid, low-status work, and that the 'high' minimum wage prevents employers employing disabled people currently out of work.

Reclassification of disabled beneficiaries

If the recommendations of the WWG's report are adopted all beneficiaries apart from a small minority (the terminally ill and single parents with very young children) will have a new status of 'jobseeker' and access to a basic benefit, less than the current rates, with additional supplements for various assessed needs (described in recommendation 21, p.112). Our experience suggests that this layered system will mean frequent visits to the new agency Employment and Support New Zealand, more paperwork and more bureaucracy. The WWG further argues that this renaming removes the disabling connotations of terms such as 'widow's

benefit', 'domestic purposes benefit' and 'invalid's benefit' (WWG, 2011, p.14). Its concern for the well-being of invalid's beneficiaries re-emerges later when it suggests a new term for 'case management', which disabled people find 'old-fashioned and demeaning' (ibid., p.88). It suggests instead 'co-ordination' and 'co-ordinators'. This renaming from on high is not only highly ideological but also patronising.

Recommendation 13 (ibid., p.24-5) outlines the new assessment process

(Gentleman, 2011). Their 'simple tool' is a computer-based checklist administered by a private multinational company, Atos, with incentives to reduce beneficiary numbers and rewards including further contracts, something also promised by the WWG (WWG, 2011, p.116). Critics decry the lack of any relationship between assessor and disabled person, and that there is no account of medical or other history such as mental health. 'Invisible' impairments are often overlooked. Those who don't

birth to prevent bullying in schools, support for families so that those with disabled children don't break up, housing, transition support, mental health support, training for employers, skilled professionals who understand' (Asperger's Syndrome New Zealand, 2010).

Simplistic solutions disguise other fish-hooks, such as the suggested removal of the invalid's benefit from disabled 16-17 year olds, a group who find it hard to get after-school work and have more transport, personal and other expenses than their non-disabled peers. Disabled parents are another group with complex support requirements. Additionally, the elimination of the child disability allowance alarms, as that small amount is vital for many parents, enabling them to get essential support for their disabled child.

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which includes a 'simple' assessment tool and various levels of support, from none – 'self-directed job search' – to support for those considered to have no 'employment expectations'. As a cost-saving measure the WWG suggests that this 'work assessment process would leverage off new computer-based systems being developed to enable patient records to be accessed by multiple medical practitioners and across organisations' (p.69). This raises the possibility of the emergence of a screen-based bureaucracy in which decisions are formalised, standardised and pre-programmed, squeezing the space for discretion (Bovens and Zouridis, 2002) when this discretion is vital in assessing ability and the degree to which one can work. In the case of disability, one would expect that a just system of work assessment would be highly personalised and nuanced in order to provide an accurate reading of the person's capacity to enter paid work in light of his or her impairment.

This process describes what has been recently implemented in the United Kingdom where extensive 'welfare reform' is also taking place, in which disabled people are also being reclassified as 'jobseekers' with access to contestable additional supplements. However, it is causing a backlash across the disability sector for its insensitive and inappropriate methods

score enough points are moved onto the 'jobseeker's allowance', which is about a quarter less than the current benefit and provides no employment support. Those scoring higher are classified as those deemed capable of work but requiring employment support and those deemed too disabled to work. This new system has already resulted in a large and expensive appeals process. Such a scoring process also harks back to the 'human worthiness' gradings of New Zealand's 1911 Mental Defectives Act.

Discussion

We agree that in New Zealand the lack of quality, flexible, adequately-paid work opportunities, particularly for disabled people, is problematic. Currently many are forced to survive financially on a stretched welfare system, and consequently many endure poverty, poor health and poor educational outcomes. But labelling it as a problem of individual 'welfare dependency' which can be solved by harsher compliance requirements has framed the argument too negatively, and has caused many of the WWG's more positive suggestions, such as more cross-government collaboration and better education, training, employment support and child care, to be overshadowed. Many disabled people have much to contribute to society but require 'investment from

Conclusion

There are policy lessons to be learned here. Government must appoint disabled people to all working parties whose brief affects disabled people. Without this lived experience there cannot be authentic understanding of the nuances of historical oppression of disabled people, the complexity of disability, nor the disabling nature of society. When pākehā no longer speak for Māori and men for women, why should the 'able' speak for disabled people? Recommendation 36 of the WWG report suggests that implementation be supported by 'an Advisory Board (involving expertise on social policy, welfare delivery, organisational design, managing a forward liability, and Māori and employer perspectives)' (p.33): again the lived expertise of disabled people is overlooked. To make progress on such a complex issue as welfare in 2011 requires respect, credibility, partnership, and a willingness to value and enhance lives. Without it we fear a policy opportunity has been squandered.

1 There was wide cross-party support for retaining the NZDS when the question was raised during the 2008 general election campaign.

2 The current Canadian model is based on welfare insurance.

3 The first disability commissioner is about to be appointed, but this will be a role within the Human Rights Commission; disability service provision is still considered a responsibility of the 'health' system.

Human stories and implications of the WWG report:

Andrew is a young man with intellectual impairment. He is a valued part-time worker in a government agency but it cannot afford to extend his hours. The job was gained through a supported employment programme, and he received intensive employment support for the first year. He also volunteers with social groups of younger disabled people. He boards with his sister and her family as he cannot afford to live independently and still has support needs himself. He has been on the invalid's benefit for ten years and is classified as a long-term beneficiary. Under the new system he will most likely be reclassified as a jobseeker and on a lower benefit rate.

Patrick has been a beneficiary for most of the last 20 years and has had a long history with mental health services. A few years ago he heard about Asperger's Syndrome, which he suspected explained the difficulties in his life. As there is no adult autism diagnostic pathway in the public system he obtained a private diagnosis at the cost of several hundred dollars, which he is still paying off. He is a valued community member, always available to mind houses or pets. He has had several short-term jobs but is always fired

after a few weeks as he often does not fully understand what is expected of him. His dream is to have a second-hand goods shop, but he cannot afford a phone line, let alone obtain the capital to start such a venture. He is an expert on the welfare system, having been cut off many times due to communication issues, lost files, or incorrect paperwork, and regularly has to explain his situation to new staff. Under the new system he would probably be reclassified as a jobseeker without any supplementary support.

Jane's husband left her when their autistic daughter was three. Now she is at school, and Jane is keen to find work or training to get off the DPB, but there is nothing available in her provincial town and she cannot afford a car, or broadband for online study. Her daughter is ineligible for any support through the ministries of Health or Education. The school often rings Jane to ask her to collect her daughter as they cannot cope with the girl's behaviour, and she is not allowed to go on school outings unless Jane attends as well or pays for a teacher aide. How would the new recommendations address her complex multi-agency issues?

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