



Up Where We Belong

Raising the status of
disability support work

A paper prepared by the Public Service Association Te Pūkenga Here Tikanga Mahi
and the Service and Food Workers Union Nga Ringa Tota
in support of the Up Where We Belong campaign

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UP WHERE WE BELONG: RAISING THE STATUS OF DISABILITY SUPPORT WORK

1. Introduction – our campaign

The New Zealand Council of Trade Unions Te Kauae Kaimahi (the CTU), the Public Service Association Te Pūkenga Here Tikanga Mahi (the PSA) and the Service and Food Workers Union Nga Ringa Tota (the SFWU) are collaborating on a joint campaign with a view to raising the status of disability support work and build widespread recognition of the contribution of disability support workers to the well being of those who experience disability, and their participation in New Zealand society. That campaign is called *Up Where we Belong*.

Our campaign seeks to raise the awareness of the public about the disability sector and the complexity and responsibility of the work undertaken by support workers. These are workers on low wages, who have responsibility for supporting people with disabilities (and their families) to lead ordinary lives. Their work requires judgment, skill and patience. These workers are particularly vulnerable at a time of economic recession. The campaign is a means of keeping their issues before the government and being proactive about their pay (and the funding that supports it) rather than merely accepting that the economic situation will rule out meaningful increases.

The status of these workers reflects the status of those with whom they work. The campaign is therefore as much about challenging accepted community assumptions about disability as it is about the workers and what they do. The focus of the campaign is on getting improved wages and conditions through improved funding, but the government is more likely to respond those challenges if the public has a better understanding of disability and respect for those who work in the sector.

The PSA, SFWU and CTU are working with employers and consumers to promote this campaign, and utilising the knowledge experience and ideas of support workers themselves in pursuit of its objectives. Activities so far include a series of regional seminars for members and delegates, and a Disability Support Workers' Awareness Week. Employers, consumers and support workers have been involved in those, reflecting the support within the sector for the aims of the campaign and postcards have been sent to Minister Turia.

There are several terms that have been applied over the years to the workforce our campaign is on behalf of. Support worker, community support worker and unregulated worker are just some of the titles used while others have been proposed to try and reflect the level of responsibility these workers undertake. For the purpose of our campaign and this paper we use the term 'disability support worker' to make clear which workers, and which sector we are talking about.

2. Background

2.1 The disability sector at a glance

The 2006 national disability survey indicated that around 660,300 or 17% of New Zealanders report that they have a disability¹. In 2006, 82 percent of people with disability were adults living in households, 5 percent were adults living in residential facilities and 14 percent were children (under 15 years) living in households. The percentage of people with disability increased with age, from 10 percent for children aged less than 15 years to 45 percent for adults aged 65 years and over. Nearly all adults living in residential care facilities reported having a disability (99.7 percent) and most had multiple disabilities (94 percent) and high support needs (82 percent).

Approximately 33,700 (5% of those with disabilities) reported an intellectual disability², however IHC estimates that there are over 50,000 people with an intellectual disability living in New Zealand.³ 90% of the Ministry of Health's adult residential facilities were coded as intellectual disability in 2008.⁴ While this campaign is about disability support workers in general, the campaign is focussed primarily on those working in providers funded by the Disability Support Services of the Ministry of Health, who are mainly involved in working in support of those with an intellectual disability.

Data from the Ministry of Health's Quality and Safety Project suggests that the support workforce funded by Disability Services in the Ministry of Health is somewhere between 19,000 and 22,000 workers, with an overlap between home-based and residential services of approximately 7%⁵. The survey of providers conducted in support of the project also identified that approximately 10% provided home based services, 45% residential, 23% a mix of residential and home care with around 22% not specifying.⁶ A clear majority of these were providers of care to those aged over 65. Again this campaign is focused on adult residential and homecare services being delivered to adults with disabilities.

¹ Statistics New Zealand, (2007) "Hot off the press" 2006 Disability Survey Report – source for all the following data

² [http://wdmzpub01.stats.govt.nz/wds/TableViewer/tableView.aspx?ReportName=Disability/Adults with disability, by disability type, age-group, sex and place of residence, 2006](http://wdmzpub01.stats.govt.nz/wds/TableViewer/tableView.aspx?ReportName=Disability/Adults%20with%20disability,%20by%20disability%20type,%20age-group,%20sex%20and%20place%20of%20residence,%202006)

³ IHC, (2008) cit. Bonardi, A. (2009), *The Balance between Choice and Control: Risk Management in New Zealand Intellectual Disability Services*, Fulbright New Zealand

⁴ Conversation with Rob Gill, Ministry of Health (18 August 2009), reporting on discussions of funding allocations under the Leadership Development Scheme in 2008.

⁵ Chal J. (2004) *Disability Support Services in New Zealand: The workforce survey*, Wellington, Ministry of Health cit. Ministry of Health (2009) *Disability Support Services Workforce Action Plan* p. 11

⁶ Chal J. (2004) , *Disability Support Services in New Zealand: Part 1, Service Provider Survey* p. 17

2.2 A brief history of disability support services

For most of New Zealand's history support services have been dominated by the medical model, in common with much of the western world. The early 20th century saw the establishment and expansion of institutions for people with disabilities and parents and families were encouraged to place their children in care settings outside the home⁷. There was a growth of special residential schools and specialist institutions.

Through the 1940s into the 1970s there was continued growth in the numbers of people living in institutional settings (although by 1981 nearly half those with intellectual disability were living in special wards in psychiatric hospitals.)⁸. This has become known as the 'medical model' of care.

By the mid 1970s there was growing realisation that institutional living often compromised the quality of life for individuals experiencing disability. 1975 saw the adoption of the Declaration of Rights for Disabled Persons by the United Nations General Assembly. There was recognition that institutional care was essentially paternalistic, robbing them of the dignity of being able to exercise control over their daily lives and, at times, exposing them to abuse.

The high proportion of nurses on the staff of institutions such as Kimberley Centre, where an on-site School of Nursing was established in 1959 teaching a specialist 'psychopaedic' curriculum,⁹ reflected this medical model.

The Disabled Person's Community Welfare Act (1975) was the first legislative recognition in New Zealand of the paternalism of institutionalisation, providing greater support for individuals living in the community. The Act was administered by the Department of Social Welfare, rather than by health, which was symbolically important. This represented the first shift away from the medical model to a 'social model'.

In contrast to the medical model, the social model emphasises that attitudinal and environmental barriers created by society hinder the independence and participation of people with disabilities; it is often associated with a recognition that people with disabilities have the same human rights as their non-disabled peers¹⁰.

⁷ *ibid* p.10

⁸ Milner, P. (2008), *An examination of the outcome of the resettlement of residents from the Kimberley Centre*. Dunedin, Donald Beasley Centre p. 8

⁹ *ibid* p. 8

¹⁰ Social Services Select Committee (2008) *Inquiry into the quality of care and services for people with disabilities* p. 9

The 1980s was the period in which the drive for de-institutionalisation gathered momentum driven by the principle of 'normalisation'.

Although criticised later for being assimilative and for de-emphasising (bodily) difference, the normalisation principle drove the process of deinstitutionalisation. As it became more widely embraced, the philosophy of normalisation insisted best practice required people with intellectual disabilities to be reintegrated within the normal spaces and rhythms of the wider community. Normalisation became both the goal and guiding principle of community-based service practice.¹¹

In 1985 the government announced it was adopting a policy of community living for all people in long-stay institutional care. By 2006 the closure of Kimberley Centre represented the end of large scale institutional care for people with intellectual disability (and for people with disability more generally).

In the 1990s the structure of disability support services as we now know it, was begun to be put in place as part of the overall reform of the health and disability system along market lines. Funding for disability supports was shifted from the Department of Social Welfare to the Ministry of Health. The Disabled Person's Community Welfare Act had established a statutory right to services and the health and disability reforms replaced this with a model in which there was a limit on funds.

As a result, rationing, and prioritisation became very real features of the service model, and valid methods of assessing need and support available became essential.¹²

This was reflected in the Disability Support Services Framework, which included a model in which needs assessment and service co-ordination were separate from service provision.

A competitive environment was established in health and disability services and new providers were encouraged to compete for service contracts from the Ministry of Health. The reforms promoted greater consumer choice, which accorded with the aims of disability advocacy groups, while establishing a means of managing costs and driving efficiencies.¹³

¹¹ ibid p. 9

¹² Bonardi p, 12

¹³ Ibid p. 13

With the establishment of the District Health Boards in 2000, which was accompanied by the devolution of funding of health services to the DHBs from the centre, disability support services funding (for those aged under 65) remained with the Ministry of Health.

Since that time a number of significant strategic reports have had an influence on how services for people with disabilities are delivered. Most important of these was the *New Zealand Disability Strategy 2001*¹⁴, which is a government-wide, long-term plan based on a vision of a society in which people with disabilities are able to fully participate.

*To Have an Ordinary Life*¹⁵ was produced by the National Health Committee in 2003 and found that people with intellectual disabilities did not have the ability to make choices over important issues such as housing nor the support to achieve their aspirations and goals.

The Report of the *Social Services Select Committee: Inquiry into the quality of care and services for people with disabilities*¹⁶ arose out of concerns about the support services provided for people with disabilities in New Zealand. The report identified problems such as a lack of leadership, fragmented services, geographic variability in the quality of services and ineffective implementation of the New Zealand Disability Strategy.

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 was designed to enable the compulsory care and rehabilitation of intellectually disabled people who have been convicted or charged with an imprisonable offence. As of September 2008, 135 people were under compulsory care orders.¹⁷

2.3 The structure of disability support services

Disability Services (DS), part of the Health and Disability National Services Directorate, is responsible for the planning and funding of disability support services, administers the Intellectual Disability (Compulsory Care and Rehabilitation) Act (2003) and provides policy advice to the Minister of Health. Following the Government's response to the 'Horn Report' (see 6.2 below)

¹⁴ Ministry of Health (2001), *New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga*. Wellington, Ministry of Health

¹⁵ National Advisory Committee on Health and Disability (2003), *To Have an 'Ordinary' Life: Community membership for adults with intellectual disability*. A report to the Minister of Health and the Minister of Disability Issues, Wellington, National Health Committee

¹⁶ Social Services Select Committee (2008) *Inquiry into the quality of care and services for people with disabilities*

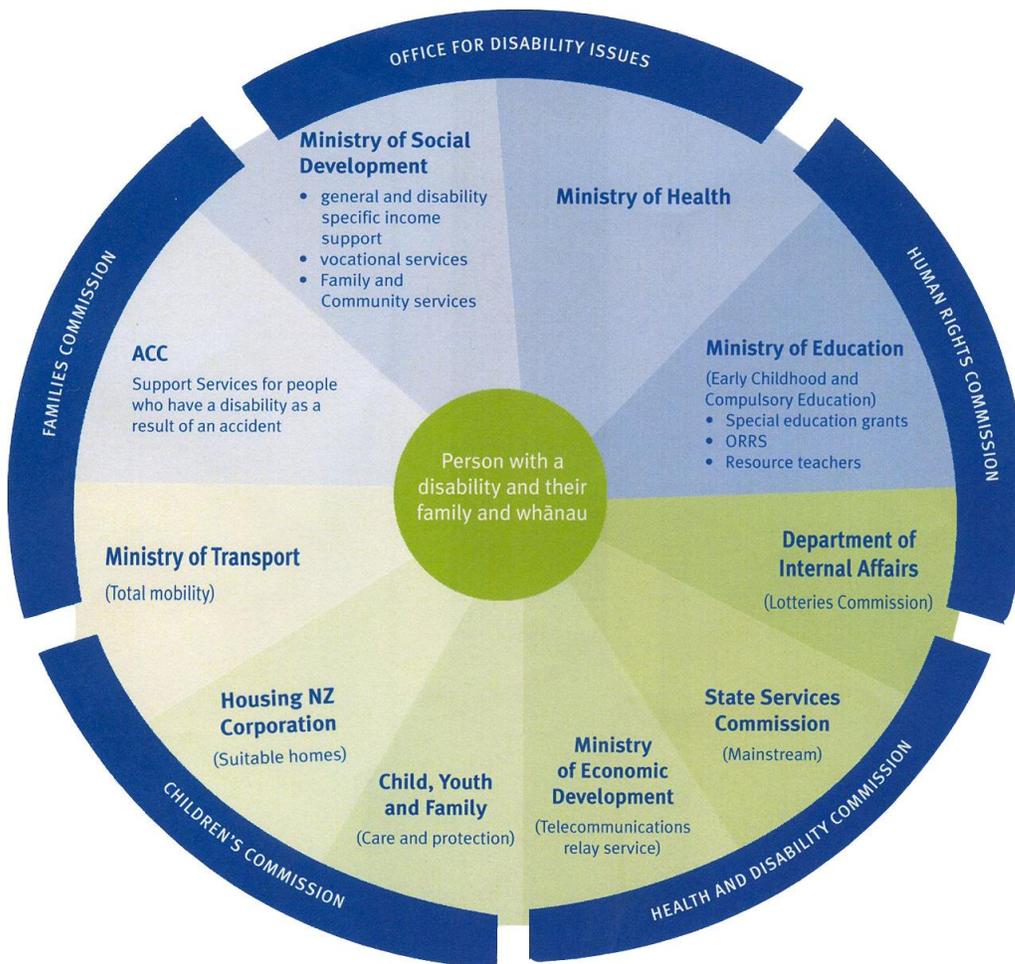
¹⁷ Daysh, R. cit. Bonardi p. 27

disability services has moved into the National Health Board and may be subject to further changes as the transition process rolls out.

Many of the services DS funds are accessed through a Needs Assessment and Service Co-ordination (NASC) service. NASCs are independent organisations contracted to the DSS, which work with disabled people to help identify their needs and to outline what disability support services are available. They allocate Ministry-funded support services and assist with accessing other supports. In this they act as gateways to services.

The Ministry of Health is one of a number of government and non-government agencies that fund disability support services.

The diagram below demonstrates the relationships.



Source: Ministry of Health. Disability Services Workforce Strategy and Action Plan.

The Office of the Health and Disability Commissioner, the Office for Disability Issues and the Human Rights Commission are key agencies that help protect the rights of disabled people. The Office of Disability Issues also acts as an overseer of the implementation of the New Zealand Disability Strategy among government organisations. The Ministry of Health has several directorates that are involved in the disability sector, however DS is the main funder of disability supports.

Ministry of Health funded disability support services are services or products that help disabled people carry out their daily life. These supports may include equipment, such as wheelchairs, housing or vehicle adjustments, or someone coming to their home to help them with managing their home or with personal care. It may also cover the normal carer taking a break. It also includes funding for community residential services, where people with disabilities live in small group homes in the community, supported by disability support workers.

The focus of the *Up WhereWe Belong* campaign is the funding and services provided through the Ministry of Health.

3. Funding Issues

3.1 Ministry of Health funding

The Ministry of Health has been allocated \$895 million dollars in the 2009/10 budget for disability support services. This is up from around \$890 million in 2008/9 and around \$834 million in 2007/8. This represents an increase of around 7.3% from 2007/8.

Over the same period overall DHB funding increased from around \$8.6 billion to \$9.6 billion or around 11.5%.

In light of the recession, the signal from government is that there will not be any significant increase to these funding levels in the foreseeable future, placing further pressure on the already low wages of disability support workers.

In 2008/9 the main areas (and amounts) of funding provided through Disability Support were¹⁸:

Needs Assessment Service Co-ordination (NASC)	\$17.1 million
Disability Information Advisory Service	\$9 million
Home and Community Support Services	\$177.3 million

¹⁸ Ministry of Health, briefing paper to the Disability Tripartite Forum, November 2008

Residential Services	\$379 million
Environmental Support Services	\$109.7 million
Day programmes	\$29.5 million
Child Development Services	\$21.8 million
High and complex services	\$76.2 million

Home care and residential services, which is where disability support workers are overwhelmingly employed, are the two most significant budgetary items.

3.2 Funding of providers

Within the overall Ministry budget, funding of providers has been ad hoc and inconsistent. There is as yet no standard and consistent approach to funding residential and homecare disability support providers. Overall there is a consistent set of service specifications (which sets out the service expectations) that applies to all providers, but this operates in the historical context of funding to each provider.

One of the variables is the legacy from the previous Regional Health Authorities, which funded providers on a different basis across the country, reflecting such regional variations as the different approach of local authorities to charging for water. This has not yet worked out of the system.

In addition funding for the major providers has evolved in different ways. For example, IHC (the largest provider in the country) has been operating under a form of transparent pricing implemented in 2003, but it does not as yet apply to any other provider. In addition, individual providers facing particular pressures (such as the likelihood of industrial action over wages) have been able to negotiate extra funding to head off a crisis.

There are two ways that funding to a provider can increase: the first is when the budget allocates additional funding - this comes through as a percentage increase in funding (although the percentage might vary according to provider); the second is when the needs of a client increase and the provider asks for a reassessment of this client to occur. The needs assessment agency (NASC) then recommends an increase to meet these needs. Assessments are supposed to take place on a regular basis.

In 2007/8 providers were advised that due to reassessment of a significant number of clients, which saw a large number move to a higher level of funding, no percentage increase would be forthcoming. In a move that reflects the variable and ad hoc funding regime that applies, additional funding was found but it was not applied to the two largest providers in the sector.

Most providers supply services to a range of client groups and in different settings. Home care for those with life-long disabilities and over 65s; residential care for those with life-long disabilities and over 65s; and respite and day care services for those with life-long disabilities and those aged over 65. This means that they receive funding from several different sources, if they provide services in different district health board areas. DHBs fund most home care services and services for over 65s. They also fund mental health services and some providers deliver services to people with mental health issues as well as those with disabilities. Some providers are also providing supported vocational services which are funded through the Ministry of Social Development. The inconsistency in funding arrangements can be frustrating and can incur significant administrative and compliance costs. The inconsistency can also be passed on to workers in variable pay and conditions, depending upon the contract they are working under.

3.3 The transparent pricing model

The Ministry of Health has been working to establish a consistent transparent pricing model to purchase residential services for people with an intellectual disability. The purpose is to consolidate the funding models used by the Ministry .

The model would factor in various assumptions such as the pay and conditions of staff, housing costs, transport, household food and supplies and power and do so in a consistent and transparent way.

The project has been underway for several years and appeared to be close to completion with the development of transparent pricing model tools and training in February 2007. However since that time a number of problems have transpired, effectively putting the whole project on hold. Providers and unions both felt that the model significantly underestimated the costs involved. Unions were particularly concerned about the assumptions over hourly rates and sleepover costs.

The model has also struggled to get consistency in application across the various NASC agencies around the country. Assessors have to use their judgement and this inevitably leads to variation. The PSA, the SFWU and the CTU remain committed to the idea of a transparent pricing model, but much more work has to be done to make it a reality.

3.4 Funding and wages

These problems matter to disability support workers because the level of funding drives or constrains the level of wages that providers can afford to pay.

- A transparent pricing model, based on fair assumptions about wages and consistently applied is essential if decent pay for disability support workers is to be achieved.
- The model must also be properly funded by government. This means the government's budget for disability services must be increased in recognition that workers in the disability sector are underpaid for what they do.
- 'Clipping the ticket'. Funding provided for wage increases must be passed on to the workers, without funders or providers taking a contribution out of the funding as it passes through their hands. This is a particular issue where providers are 'for profit'.

4. The Disability Support Workforce

4.1 The evolution of the disability support workforce

With the increase in institutionalisation from the 1940s onward there developed greater recognition of the need for adequate staffing and adequate training for staff. In the 1960s occupations for the care of people with intellectual disabilities were being described in terms of providing diagnosis, care and rehabilitation.¹⁹ Better staff:patient/resident ratios and better training were introduced for medical, therapeutic and safety reasons.

For example, at the Kimberley Centre there was not only an on-site School of Nursing for the training of psychopaedic nurses, but also a National Training School that ran course for training officers who worked alongside those nurses. However, the former was disestablished in 1991 and the latter in 1989 so that by the time that Kimberley closed in 2006 a substantial proportion of the staff were untrained and unqualified²⁰. This was representative of the running down of training capacity within disability support.

While much of the training of staff in the institutionalised model reinforced the paternalistic and medical models of care, it was replaced with very little for staff who worked in the support of people with disabilities from 1990 onwards. Training was substantially left up to employers whose

¹⁹ Gates, S.(2008) *The Impact of De-institutionalisation on the Staff of the Kimberley Centre*, Dunedin, Donald Beasley Centre p. 3

²⁰ Ibid p. 9 The staff at the Kimberley Centre at the point of closure included management and administration staff, registered nurse educators, registered Nurses, enrolled nurses, 'psychopaedic' nurses, psychopaedic assistants, and a range of maintenance staff.

response to the challenge has been variable. As the PSA said in its submission to the Social Services Select Committee Inquiry:

The move to community based services required a higher level of autonomy from support staff and therefore a higher level of expertise and skill but paradoxically the shift has been characterised by reduced access to training, reduced levels of supervision, and reduced access to peer support and expert advice²¹.

Until we can reintroduce professional training that is recognised across the sector, increasing wages for support workers will be difficult.

Qualified staff, directly employed by the state, have historically been able to maintain fairer wages and conditions than those in contracted out services. Since the model of support has changed with de-institutionalisation, pay and conditions for the disability support workers (who have become the predominant workers in the sector) have slipped well behind equivalent workers within the DHBs. This reflects the pressures of the market model of funding for disability support services:

It could be argued that the government model to promote marketplace pressures (competition) was only prepared to devolve risk to the level of providers because of the accountability and control that it could exert as the major funder. Without an 'industry' or 'programme' that includes monitoring accountable to the funder, it is difficult to ensure accountability of government funds²².

This distance between the funder and the provider thus enables the government to distance itself from the effects of its decisions about funding levels, including the wages and conditions of the workers. until we can reintroduce the professional training that is recognised across the sector increasing wages will be difficult'

4.2 The disability support workforce today

Disability support workers are the single largest group working in the disability sector today, but it has been difficult to establish actual numbers. In 2001 the Health Workforce Advisory Committee estimated that there were about 30,000 'informal support workers' working in disability support

²¹ NZ Public Service Association Te Pūkenga Here Tikanga Mahi, (2006) *Submission to the Social Services Select Committee Inquiry into the quality and care of service provision for disabled people and how they might be improved* p.4

²² Bonardi, p. 14

services²³. A probably more accurate figure was contained in information provided to the Quality and Safety Project in 2004 by Auckland University,²⁴ which estimated that there were between 40,000-50,000 support workers employed by New Zealand disability support services. Of these some 19,000 – 22,000 worked in services funded through the Ministry of Health Disability Support Services.

The Auckland University study identified that disability support workers were typically female (93%) and middle aged (76% were aged 40-69)²⁵. The gender split contrasts with that applying at Kimberley for example, where of the 349 staff there just prior to closure, 61% were male and 39% were female²⁶. The gender shift suggests that the move to a largely unqualified workforce was coincidental with a shift to a female dominated workforce.

Ethnicity data, although uncertain, implied that roughly 14% of the overall support workforce in 2004 was Māori, 5% Pacific peoples and 2.5% Asian, with the remainder being Pakeha. Anecdotal evidence from the unions suggests that migrant workers represent an increasing proportion of disability support workers.

The Auckland University study found that home support workers were predominantly part time, casual (paid by client contact) and that 75% worked less than 25 hours a week. 62% of residential care workers worked 30 hours or more a week.

4.3 Working conditions

The work of disability support workers is often difficult and demanding, although immensely rewarding. The conditions under which they work are often substandard and place them, and their clients, at risk.

The Auckland University study found that in 2004 support workers perceived risks to their safety (55% felt they might get hurt or injured at work) associated with providing personal care, verbal abuse from clients, conflict with other workers or issues with management²⁷.

²³ Health Workforce Advisory Committee (2001) *The New Zealand Health Workforce: a stocktake of issues and capacity*

²⁴ Chal, *ServiceProviders Survey* p. 4

²⁵ Chal cit. Ministry of Health Paper prepared for Low Pay in Aged Care and Disability Sector meeting 16 February 2007

²⁶ Gates, p.8

²⁷ Chal, *Workforce Survey*, p. 86

“My knees and my arms ached at night. I’d wake in the morning with my hands tingling with pins and needs from the repetitive strain of manipulating the hoists. I had to have a break from that house or I’d have needed a knee replacement in 10 years.”

Community House Leader

‘Sleepovers’, for example, are poorly paid and represent a cost cutting measure to avoid night shifts or ‘wakeovers’ where staff have to stay awake during the night. Staff sleep in the residences of the people they are supporting, often in poor conditions with a bed made up in the lounge. They are spending eight hours away from home and are paid a sleepover rate generally ranging from \$35.00 to \$50.00. . The concept of sleepover is exploitative and takes advantage of low paid employees who have little option but to do sleepovers to earn additional income.

There are “dangerous conditions for some sleepover staff, for example, sleeping in the lounge of a volatile residence. There is a lack of privacy.”

Residential disability support worker

Precarious hours of work are a feature of the disability support service and this is particularly acute for home support services. Hours of work fluctuate depending on the changing circumstances and needs of people being supported. There is a lack of standard hours and workers have no guarantee of hours of work in the home care sector. Home support workers can arrive at a client’s house and be advised “not today” or that the client is in hospital or even dead. In these circumstances the worker may not be paid.

There is a recent history of very high turnover in the disability sector. In 2004 turnover was 39% in home based services and 29%²⁸ in residential care (aged care and disability) and the median length of employment was 24 months. The National Residential Intellectual Disability (NRID)

²⁸ ibid

providers group reported that their staff turnover in 2007 was 22% on average, compared with 28% in 2006.²⁹

High turnover contributes to the staff shortages in the sector. It is not uncommon for support workers to work long hours in order to cover when there is not enough staff for each shift. Union delegates report that members work long hours (100-110 hours a fortnight) which is unsafe but understandable given the workforce shortages.

"We're struggling to staff this house. We're down two full time staff. People wear out. The money is not fantastic the job is physically and mentally demanding and you work antisocial hours. "

Residential disability support worker

The recession is likely to have reduced turnover rates since then, but this does not represent a solution to the problem. If people are staying in the job when they really want to move on, it is likely to make for a more unhappy workforce, with implications for quality of service. A sustainable solution is needed, that addresses wages and conditions.

4.4 Pay and conditions of employment

Disability support workers are low paid workers. Rates of pay in Ministry of Health funded services start at about \$14.20 an hour (as at July 2009) with the prospect of increasing to around \$17 an hour after a few years experience.³⁰ This compares to the minimum adult wage of \$12.50 (as at 1 April 2009) and the average wage of \$25.09 an hour (as at 30 June 2009).

As has been pointed earlier, when disability services were provided by the state (rather than just funded) wages were relatively higher than they are now - yet the job has become more demanding for support workers. This reflects the market developed in the disability sector in the 1990s, which meant that wages were driven down by providers in response to the pressures of the contracting regime. It also reflects the feminisation of the workforce (where the skills of

²⁹ Grant B. (2007) *National Residential Intellectual Disability Providers Salary and Wage Survey Report*. Hamilton, Opinion Research cit. Ministry of Health, *Disability Services Workforce Strategy and Action Plan* (Final Draft October 2008) p. 13

³⁰ An average of pay rates from some of the largest providers covered by the PSA. Rates applicable as at July 2009.

women are valued less than those of men³¹) and a devaluing of the disability sector - both workers and people with a disability.

In the Auckland University study in 2004 wanting better pay was the most common reason given by workers interviewed for thinking that they might leave their job. Other reasons included difficulties with client, the physical demands of the job and the stress.

The pay scale doesn't match the job description. There is high accountability for support workers but limited training and resources and low pay

Disability Support worker

Low pay contributes to the staffing shortages that the sector has experienced in recent years, with union members reporting that comparable wages are being paid in the fast food and supermarket industries.

4.5 Valuing the skills

Providing appropriate disability support is complex and challenging work and must meet the individual needs of people. The focus is on a support role i.e. working with people with disabilities in a developmental way to enable them to live as full a life as possible, rather than on a purely caring role. This is consistent with the social model of disability support.

Disability support workers need a wide range of skills including problem solving, physical dexterity, being observant to changes in behaviour or well being and judging how best to respond (as well as reporting on this). They do this with less professional support than was available to their predecessors in the large institutions – they have a high degree of autonomy.

Some people requiring support have dual diagnosis (mental health and intellectual disability), others have sensory and/or physical disabilities as well as an intellectual disability. Some exhibit extremely challenging behaviour, others require minimal assistance to live independently in the community. Others are medically fragile and/or technology dependent.

All require and deserve high standards of care and support to live as full a life as possible. Providing the support and care required for the individual needs of people is complex and challenging.

The challenges facing support workers are likely to increase as thinking about the care and support of people with disabilities evolves. For example, to live an ordinary life means that people

³¹ See the comparison between disability support workers and corrections officers below.

with disabilities should have the right to take more of the kind of risks that able-bodied people do in their day-to-day living.

To be confident supporters of risk taking, people who provide supports must possess skills beyond basic risk identification and developing a risk plan. They must have developed skills in:

- *Multidisciplinary interactions, including a common understanding of risk and the ability to effectively empower, challenge, and support people.*
- *Negotiation, including the ability to clearly state positions and goals, identify boundaries (i.e. clear issues of person safety), and be prepared to 'agree to disagree'.*
- *Facilitation, using empowerment strategies in order to encourage people "to have more say over their lives, but also to assume responsibility for their decisions in relation to risk."³²*

These are advanced skills, well beyond the basics of personal care, which are not reflected in the wages paid in the sector.

The type of skills required are often difficult to identify, which contributes to their being undervalued. This is not unusual for low paid predominantly female occupations and work has been done on describing and recognising them as 'articulation skills'.

...much service sector work... is best analysed through the conceptual framework of articulation work. This framework emphasises that integrating the elements of individual tasks and roles, and folding them into the ongoing flow of one's own work and that of the workplace, is a special 'supra' form of work³³.

This means not only recognising the elements of the tasks and challenges disability support workers face but also the skill involved in integrating these into getting the job done effectively. The concept of articulation work could serve as the basis of both a meaningful career path and financial recognition.

In recognition of the fact that the work of disability support workers was undervalued, the PSA commissioned a gender-neutral job evaluation exercise, which compared the work of disability support workers with therapy assistants in hospitals and corrections officers in prisons³⁴.

³² Bonardi, p.65

³³ Hampson, I., Junor, A. and Barnes (2007), *Articulation Work Skills and the Recognition of Call Centre Competencies in Australia*, Sydney, UNSW p. 4 . See also the work of Anne Junor for the Pay and Employment Equity Unit of the Department of Labour , *Report on the Service Sector Skills Identification Project* <http://www.dol.govt.nz/services/PayAndEmploymentEquity/resources/peeu-forum-presentations/junor.pdf>

³⁴ PSA (2008), *Community Support Workers: a job evaluation exercise*

The Department of Labour Equitable Job Evaluation system was utilised. This system was developed to provide a job evaluation tool that can fully describe and measure key aspects of all jobs including previously under described and undervalued aspects of female dominated work. The system was tested by a working group of job evaluators and equity experts. In order to use the system, the PSA had to meet the conditions of use set by the Department of Labour, including assurance that the consultant using the system was fully competent to do so.

Quality control was assured by having job holders and their managers verify that the job information obtained by the consultant is an accurate and fair representation of the job. In addition, an external independent consultant validated the evaluation results.

The PSA chose therapy assistants and corrections officers based on the following criteria:

- entry requirements to the occupation - none of the three has mandatory entry qualifications.
- level of occupational classification within the Australian and New Zealand Standard Classification of Occupations 2005 – the classification indicated the predominant skill level of each of the sub-major occupational group. All three occupations were described as being skill-level 4.
- the level of the professional qualification available to the occupation - after appointment, there are formal qualifications at equivalent NZQA levels (supported by the employers) available to staff.
- gender occupancy – disability support workers and therapy assistants are both predominantly female occupations, whereas corrections officers are predominantly male

The weighted total scores for the three jobs were similar (full report available through the PSA). The data supports a view that these jobs are of substantially similar value.

At the time the evaluation was carried out the average starting pay for community support workers was \$13.23 an hour or \$27,518 a year compared with:

- The normal starting pay for therapy assistants of \$ 29,266, \$1748 more than community support workers - a 6.4% pay gap.
- The starting pay for corrections officers of \$41,615 a year, \$14,097 more than community support workers - a 51% pay gap.

The average top pay rate for community support workers was \$16.20 an hour or \$33,696 a year, compared with :

- A top rate for therapy assistants of \$41,109, \$7413 more than community support workers, a 22% pay gap.
- A top rate for corrections officers (with internal training) of \$51,257 a year, \$17,551 more than CSWs, a 52% pay gap.

The consultant concluded that corrections officers, therapy assistants and corrections officers were jobs of similar size that could well end up in the same salary band within the same organisation. She concluded that the main reason for the differential was probably the ability to pay, because of the funding regime, rather than recruitment and retention.

4.6 Training and Career development

Training and career development are an essential component in raising pay and reducing turnover of disability support workers in the long term. When New Zealand had large institutions for the intellectually disabled, psychopaedic nurses and training officers were trained specifically in this area of work. The closure of the schools at Kimberley, without proper replacement, meant that there was little training provided in intellectual disability for either nurses, or disability support workers when they arrived on the scene with the reforms of the 1990s.

The Auckland University study found that 50% of providers said that less than half of their staff were adequately trained, more so in home-based care than residential care.³⁵ The inquiry by the Social Services Select Committee found that some people with disabilities were not able to be provided with the services they expected because of inadequately trained staff³⁶.

Our members want to be trained, however the provision of training programmes is mixed. The quality and relevance of training programmes varies across providers, as does the support made available to staff to undertake training. The qualifications available are often low-level and there is little financial incentive to upskill.

“Staff would like to get more training in the field (of disability support services) but have to do this on top of a 40 hour week. We used to have our fees paid but that isn’t offered anymore”.

Disability Support Worker

³⁵ Chal, *Service Providers Survey* p. 61

³⁶ Social Services Select Committee (2008) p. 38

Support workers report to their unions that some workplaces provide useful training that assists them to provide a better service. In particular specific training such as First Aid training, including how to perform cardiopulmonary resuscitation, non-violent crisis intervention, behaviour management techniques and education about the health needs of the people for whom they are caring is particularly useful. Other workers identify the need for training in responding to violence in the workplace and other specific skills to better understand and therefore support the disabled people they are working with.

There is also a need for more specialised in-depth training in recognition of the level of skills required.

Funding and giving staff paid release time for study were identified by the Auckland University study as the two biggest impediments to improving the qualifications of disability support workers³⁷. The Social Services Select Committee expressed concern that “requiring the workforce to pay for qualifications could also create difficulties in this low-paid area of work”³⁸.

“Use the money to help us gain the qualifications we need to do our job and pay us a living wage so we can make this a career.”

Disability Support Worker

There is some evidence to support the contention that training does contribute to a sustainable reduction in turnover among disability support workers. A Home Health Association informal survey in October 2008 found that the staff turnover for a sample of the graduates of the Home Based Support Services Training Initiative introduced in 2005 was only 16% compared with the 22% for residential disability support workers the previous year³⁹.

Some progress has been made. Careerforce (the Community Services Industry Training Organisation) is engaged on a programme of work to improve the level and range of qualifications available to disability support workers. The Disability Action Plan also noted (in 2008) that new worker orientation programmes are delivering the National Certificate in Community Support Services (Foundation Skills level 2) in the first year of employment, without the need for additional incentives⁴⁰.

³⁷ Chal, *Workforce Survey* p.116

³⁸ Select Committee p. 39

³⁹ Ministry of Health (2009), *Disability Action Plan*, p. 12

⁴⁰ *ibid*

The Social Services Select Committee noted that the health sector career framework had been launched in 2007 and that the Disability Services Consumer Consortium had endorsed the applicability of this framework to the disability support workforce in May 2008.⁴¹

However, lack of funding remains the main impediment, particularly for wages that acknowledge the qualifications that disability support workers might attain as the quality and availability of qualifications improves. There is a long way to go until the vision of the Select Committee for a “structured career path”, “value-based training” and “paid training” can be achieved.

5. The Political Context

The political context is mixed. The Social Services Select Committee with its strong recommendation for the Government to “establish a strategy for improving training, pay rates, and working conditions for the caring and support workforce in the disability sector, including those funded through Vote Health”,⁴² arose out of political concern about the problems in the sector. It indicated some political will to do something about those problems.

However, the select committee did its work under the previous government and an election has changed the political scene considerably. The National Party manifesto on disability issues acknowledged the challenges facing the sector and the workforce in particular, stating that “more needs to be done to support this vital workforce.”⁴³

However, their prescription is cautious. They commit themselves to “working towards” multi-year funding contracts for disability providers, which will provide much needed security for providers and workers. They also propose to work with the sector to “address staffing issues over time, including improved training and career pathways”. There is no mention of doing anything about low pay.

The National Party’s support parties in government are ACT, which has no policy on disability support services, United Future and the Māori Party. United Future explicitly identifies the need to include wages in contracts with providers, with an ideal starting rate of \$18 an hour. Tariana

⁴¹ Select Committee, p. 39

⁴² Ibid p. 40

⁴³ National Party(2008) *Health Policy: Disability Issues* p.1
http://www.national.org.nz/files/2008/disabilities_policy.pdf

Turia is the Minister for Disability Issues and an Associate Minister of Health. Māori Party policy on disability issues commits the party to reviewing “the work conditions, pay and training opportunities for those working in the elderly, disability and home care sectors”⁴⁴.

The financial crisis, and the Government’s resulting fiscal constraint, is also an important contextual factor. In the 2009/10 budget the disability sector received an increase in funding of 0.6%. While tiny, it was better than the new money available to many other parts of the state sector. This level of funding will not address the needs of the sector and the next year or two will probably be little different.

All of these contextual factors indicate that there is some awareness in political and public management circles of the need to do something to improve the disability support sector, including the workforce, but there is little explicit commitment to address pay. There is likely to be a reluctance to spend the money unless the Government can be persuaded of the urgency of the problems facing the disability support workforce.

6. Where to from Here

6.1 The Disability Workforce Action Plan

The main institutional response to the problems of the disability support workforce is through the Ministry of Health’s *Disability Workforce Action Plan* released in 2009. The plan is the product of two years of work and follows on from the Quality and Safety Project 2003. It aims to improve the status of disability support workers and improve their retention by provide training and career paths for the disability support workforce.

The plan is built around three phases, with particular emphasis on the need to develop a trained workforce.

Phase one is about short term goals, intended to be completed by 31 December 2010. It includes the following goals:

- Building a training framework with career pathways and agreed competencies
- Making training more accessible and sustainable
- Supporting informal carers to work safely
- Innovating to promote and reward excellent performance

⁴⁴ Māori Party (2008), *Election Policy* <http://www.maoriparty.org/index.php?pag=cms&id=130&p=election-policy.html>

- Creating more financial certainty for providers

Phase two (which is due to be completed by 31 December 2012) includes the following goals:

- Making disability support work more attractive for:
 - People who have disabilities
 - Māori
 - Pacific peoples
- Identifying and promoting the aspects of disability support careers that attract people to work in the sector
- Building additional leadership capability in the disability workforce – including informal carers

Phase three (which is due to be completed by 31 December 2014) is when the overall aim of the project is meant to be achieved. It is at that this point that funding is meant to align with the expectation to have a competent workforce delivered by the career framework developed over the preceding years.

6.2 The 'Horn' Report

The 'Horn Report' of the Ministerial Review Group set up by the Minister of Health reported to the Minister on 31 July 2009⁴⁵. It proposes a radical restructuring of the health and disability system. However, disability support services are one of the issues that the report signals as requiring further work. The workforce issues are noted in the report (including low pay) but there are no specific suggestions to deal with them, although there are some general suggestions that there is a need for greater co-ordination, simplification and flexibility in funding. The Ministry is asked to provide an early assessment of the issues identified, including any human resource issues.

6.3 A code of ethics

Disability support workers generally have high expectations of themselves, a strong sense of vocation, and come to work to do a good job. They are engaged in complex, responsible work

⁴⁵ Report of the Ministerial Review Group (2009), *Meeting the Challenge: Enhancing Sustainability and the Patient and Consumer Experience within the Current Legislative Framework for Health and Disability Services in New Zealand*

requiring high level skills and a well developed sense of judgement. The need to support the independence of those experiencing disability, the requirements of the job and the way the sector is structured means that these workers are often working in isolation having to make professional-level decisions with minimal support. They are making decisions that have a very significant ethical dimension, yet there is a limited ethical framework for them to call upon.

The Australasian Society for the Study of Intellectual Disability (ASSID) has published a code of ethics to inform the education and training of support workers, whom they call direct support professionals. The code was launched in November 2007 in Australia and in New Zealand soon after.

The Code identifies twelve ethical principles and a series of supporting guidelines. The guidelines are designed to inform the professional conduct of individual workers, for use as part of agency-based induction and in-service training and to inform curriculum content for tertiary education providers.

The content of the *Australasian Code of Ethics for Direct Support Professionals* is based on information gathered during a series of workshops conducted between November 2002 and November 2006, and a further Australasian-wide consultation during 2007. While over 300 people participated in the workshops and contributed to the consultation the unions understand that the overwhelming bulk of those involved in the consultation were based in Australia.

The ASSID Code of Ethics is a foundation document that may be adopted by organisations as it stands, or used as a starting point for organisations wishing to evolve their own Code. The New Zealand unions in the sector support this approach and see this Code as a timely initiative that will provide guidance for our members as they engage in ethical reflection about their practice and help them to improve what they do.

However it is important that the Code is 'owned' by disability support workers and not imposed or driven by employers. There is a risk that a Code of Ethics could very easily become a Code of Conduct, which would undermine its effectiveness and generate opposition among support workers.

The discussions the ASSID Code of Ethics will generate could lead to the development of a framework for ethical decision making for support workers, including the possibility of the formal adoption of a code of ethics. This could be the ASSID Code of Ethics as it stands, or a new document that develops that Code for application in New Zealand.

The unions are promoting the concept of a code of ethics for disability support workers and debate about how the ASSID initiative can be applied in New Zealand.

6.4 Other union activity – bargaining

The PSA and the SFWU engage with employers in collective bargaining on a regular basis as collective agreements expire. There are limits to what can be achieved by bargaining, which is why the unions are engaged in the *Up Where We Belong* campaign, seeking to pressure government to improve funding.

The unions use the opportunity in bargaining to promote the issues that are the focus of the *Up Where We Belong* campaign, including pay increases, better job security, funding and time for training on the job and limits on the use of casual staff.

While there is a shared commitment with employers in the sector that improved funding is essential if significant change is to be achieved, bargaining with them is still an important ongoing mechanism to make incremental improvements in pay and conditions. Bargaining strategies have been developed to ensure a consistent approach across the providers where we have members.

6.5 Other union activity – the Disability Tripartite Forum

The PSA, SFWU and CTU have established a Disability Tripartite Forum together with the Ministry of Health and employers in the services funded by the Ministry's Disability Support Services. The scope of this tripartite forum centres on funding, employment and delivery of services with a particular focus on labour/ employment issues.

The right of consumers to be involved in decisions that affect them is fully supported and respected. This tripartite group will engage with consumers over decisions and processes that involve and affect them. However, the focus of the tripartite forum is on matters that are primarily the preserve of employers and unions.

The Forum is a place for information sharing and discussion about major issues facing the sector. It has a workplan that includes providing input into such matters as workforce development, pay parity with DHBs, the development of a transparent funding model and funding levels.

6.6 Other union activity – the 'sleepover' case

Union activity is mainly focused on this campaign, but we are also engaged in a separate issue to address the longstanding problem of lack of recognition for 'sleepovers'.

The PSA was taking a case on behalf of a worker at Spectrum Care and the SFWU was taking a case on behalf of a member at Idea Services, a service arm of IHC. Both cases were heard by the Employment Relations Tribunal and both were successful in their argument that sleepovers

constituted work and both have been appealed to the Employment Court. The SFWU case has now been heard by the Employment Court

The union case was twofold: that the sleep over is work; and that it should therefore be remunerated at the minimum wage.

The Employment Court⁴⁶ found that the sleepover did constitute work but put consideration of whether the minimum wage applies on an hourly basis or whether it can be averaged, off until further submissions from the New Zealand Council of Trade Unions and Business New Zealand can be received.

The Court acknowledged some important points. They accepted the worker's evidence that there are constraints on disability workers during sleepovers:

- They may not leave the group home during the period of the sleepover with the prior permission of a supervisor and a relief worker being available and present;
- If they sleep, they must be readily available to be woken to respond to any incident in or around the home requiring their attention. This means that they may not sleep behind a locked door;
- They may not consume or be affected by alcohol or other drugs;
- They may not have visitors without the prior permission of a manager and it being acceptable to the service users in the home;
- Any activity they engage in must not disturb the service users during the night.

Disability support workers also have certain continuous responsibilities, including responsibility for the safety and wellbeing of service users. Tasks include ensuring medication is taken; property is secure; incidents are managed and incident reports are completed.

The Court noted other significant aspects of sleepovers:

- Tasks associated with the 4pm – 10pm shift did not always finish at 10pm when the sleepover was due to start.
- Disability support workers must be aware of any movement or disturbance in the house.
- The presence of the disability support worker in the house is reassuring to the service user and contributes to their wellbeing.

⁴⁶ Dickson v. Idea Services, Employment Court, (WC 17/09) 8 July 2009

- There are numerous homes where the circumstances fall between those requiring 'wakeovers' (in which the service users routinely require attention during the night) and those where a disability support worker can enjoy an uninterrupted night's sleep. Many have disturbed nights.

At all times during the sleepover the disability support worker carries a 'profound responsibility'.

The Government, in Budget 2009/10, noted that the sleepover case represented an 'unquantified risk'. By this it was meant that there was a risk that the Government may be called upon to find the money to give to the providers to fund the backpay. The potential liability for the employers/government could run into millions of dollars but there is no way of calculating the risk at the moment.

The case is a significant one for disability support workers. It recognises the challenges of the disability support worker role while focussing on the particular issue of sleepover. In this it is a major step towards recognising the value of the disability support worker. It also acts as a means of getting Government attention on to disability support workers and the need to fund better pay and conditions, and is therefore a complementary effort to the main campaign.

7. Key messages

The *Up Where We Belong Campaign* is seeking to build widespread recognition of the value of disability support work and increase its status, as an important prerequisite to improving funding for the sector and achieving parity in pay rates between disability support workers and comparable positions in DHBs (and beyond).

Our key messages to New Zealanders, and to decision-makers and those with influence are:

- Every day more than 110,000 disabled New Zealanders rely on disability support workers to help them live ordinary lives.
- Disability support workers provide support 24 hours a day, seven days a week, for people with disabilities who live in community houses. They also visit homes and support people incapacitated by a disability. Their work enables people with disabilities to be as independent as possible.
- This is demanding work that requires a wide range of skills and knowledge but it takes place out of public view.
- Disability support workers are multi-skilled, providing medical support, meals, personal care and domestic help to people with disabilities - some of whom need round-the-clock support, seven days a week.
- For this complex and demanding work they are paid as little as \$14.20 an hour, only marginally above the adult minimum wage of \$12.50 an hour.

- The low pay and difficult working conditions make it difficult to recruit and retain disability support workers and there's a shortage of staff in the disability sector.
- This is due primarily to a lack of funding from the government and the complicated and confusing way that the disability sector is funded.
- We are looking to the Government to simplify the funding system, making it more transparent and consistent, and set at a level that will ensure pay parity and better conditions for disability support workers.