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Can the New Zealand Disability Sector Work Collaboratively Together?

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Abstract

This presentation will look at the New Zealand Disability sector and ask the question: Can groups that are fragmented and trying to gain individual respect and autonomy, work together in a manner in which they can put aside individual issues and unite in one common aim. Historical events that show how fragmented the disability sector are will be described. Recent events in the disability sector will be highlighted to show that, once a level of trust between groups can be achieved, individuals can join together. However, the challenge for the future will be to maintain that level of trust.

Keywords: New Zealand, history, cooperation

Kia Ora Nga Tatou - I bring you warm greetings from New Zealand.

Background

New Zealand is a country in the South Pacific made up of a number of islands, the main ones being the North, South and Stewart Islands. It is a country that has historically been reliant upon exports from the agrarian sector. It was founded by Captain Cook in the late 1700s and colonised by immigrants from the United Kingdom who wanted to start a fresh life. In 1840 a treaty was signed between Maori, New Zealand's indigenous people, and the Crown, giving Maori partnership, participation and protection over resources.

Disabled people historically in New Zealand have depended upon family support. Tennant (1996), details the first asylum opening in 1854 providing for the care of people who were seen as mentally ill and "the first institution opened for the blind in Auckland in 1890" (p 11). Over the years, organisations that cared for people with specific impairments were formed, the League for the Hard of Hearing 1932, the Crippled Children's

Society 1935 (renamed NZCCS in 1990). The Wilson Home for children who were recovering and rehabilitating from polio was founded in 1936 and the Intellectually Handicapped Children's Parents' Association (IHCPA) in 1949 (now IHC). Between the 1950s and 1970s further institutions were established (Otara Spinal Unit, for the treatment of spinal injuries, Queen Elizabeth Hospital in Rotorua for the treatment of arthritis and the Pukeora Home for the Disabled, in Waipa). These institutions were funded through the hospital system with the aim of providing care and rehabilitation.

The IHC development is interesting. As already mentioned it was started in 1949 by a group of concerned parents. Years later it is an organisation that has 5000 employees and has an annual turnover of $150 million and, as Story (2002) indicates, has "700 homes directly under its ownership and the IHC's property portfolio worth around $120 million" (p 20).

Furthermore, Tennant (1996) believed that historically "disability organisations were dominated by the charitably-incline" (p 5) and it was not until recently that disabled people began to organise themselves into advocacy groups pushing for a "consumer voice" (p 5) within the decision making processes. This benevolence is supported by Story (2002) who lists 35 of the leading not for profit organisations that currently operate within the typical voluntary area of working with people. Of those reported only two (Deaf Association and DPA - Disabled People Assembly) have Chief Executive Officers who are reflective of the client group being served.

From the 1960s differences in terms of financial support and personal care started to develop between differing groups of disabled people. The passing of the 1964 Social Welfare Act gave blind people the ability to keep their invalids benefit even when they started in employment. This option was not open to any other impairment group and is still in place nearly forty years later. This Act also gave the spouses of those who were blind a benefit. However the spouses' benefit was stopped once they started to work. Again this option was not offered to other impairment groups, Orr (2002). On the day that people with a physical disability start work benefits are stopped. This type of bureaucracy leads some disabled people not looking for work. What is needed is a system which rewards and supports people to gain work and to gradually reduce financial reliance on the state.

Even further division between disability groups occurred with the passing of the 1972 Accident Compensation Act. This Act gave people who were injured in accidents lump sum compensation, even if they were responsible for the accident - the more severe the result of the accident the more compensation was paid. In 1996 the High Court of New Zealand ruled that the Accident Compensation Commission must provide enough monetary support so that claimants could have 24-hour attendant care "where the personal injury by accident is such, that that person must have constant personal attention" (Reserved judgement of the High Court delivered by Justice Heron, 1996).

On the other hand people who need the same level of support but have a congenital disability, or who have had a stroke etc., can receive only up to 35 hours per week attendant care. An additional allowance of hours up to 20 hours per week to provide household tasks can be given, but it is rare for the full 55 hours to be given to an individual. In monetary terms 35 hours attendant care is equal to providing 24 hour, 7 days a week care to a person in a rest home. So two people with similar support needs but with a different reason for the onset - one congenitally, the other traumatically (after 1972) - are given different levels of support, both in terms of financial recompense and physical care. One avenue leads people who are supported by the Accident Compensation to a supported life in society and the other leads people who are supported by the Ministry of Health to a life of dependency and exclusion from society in a rest home.

The Year 1981

The International Year of Disabled Persons and the Telethon held that year raised the profile of disabled people in New Zealand. From the funds raised by the Telethon, seeding funds were given to establish the Disabled Persons Assembly (DPA). One of the major differences between this organisation and others already established was that the constitution required the majority of committee members to have life experience of disability. One of the outcomes of the formation of DPA was to start to unite differing disability groups to "fight" for common issues. Since the formation of DPA other organisations have developed advocacy groups, although there arises a difficulty over how an advocacy group funded by the parent group can advocate for disabled people against the parent group.

New Zealand Disability Population Overview

Recently released 2001 census figures from the Statistician (2002) show New Zealand having a total population of 3,719,000. Auckland (located in the North Island) is the most populated region with over a million people. Of the total population 20%, or 743,800 people, reported having some form of disability. Furthermore the survey showed that disability increases with age, with the majority of disabled people reporting that they have more than one disability. Physical disability is the most prevalent. Also disability increases with age rising from 11% for children 0 to 14 years to 54% for those aged over 65.

Disability Sector

Not for profit organisations in New Zealand over the last 10 years have had to change their traditional voluntary operations into corporate structures, due to the annual budgets they now administer. A large number have budgets over the million dollar mark and this increase in budgets forces not for profits to operate in a business like manner. As well the New Zealand Government is moving to align social capital issues to the economy. This move creates the idea that the New Zealand Government shifts the responsibility away from themselves and on to community or not for profit organisations.

Story (2002) reports "New Zealand has more registered charities per capita than any other country" (p 20). This number of organisations means that the amount of money available to not for profit organisations, either through Government contracts or voluntary donations, is spread thinly, leading to competitiveness between organisations. This competition means that organisations are having to either cut costs leading to bare bone services or look at joint ventures to gain service contracts.

In Auckland a number of disability providers have formed themselves into yet another organisation, giving them a high national profile and leading to the Government only having to deal with one identity rather than a large number.

The New Zealand Disability Strategy

New Zealand had a change of Government in 1999 resulting in a Labour led coalition and for the first time a Ministerial portfolio "Disability Issues" was created. However the position was outside of cabinet, meaning effectively that the Government acknowledged that there was a need for the position but gave the portfolio a low ranking, compared to other portfolios.

One of the first roles of the Minister was to establish a reference group to develop a disability strategy that would be a blueprint for the disability sector. The New Zealand disability sector has been constantly reviewed and the feeling within the sector was here we go again. Over 700 submissions were received by the Ministry of Heath who acted as the lead agency in the process, from which an over arching vision of "a society that highly values our lives and continually enhances our participation" (Ministry of Health 2002, p 1). Along with the vision were fifteen objectives:

1. encourage and educate for a non-disabling society
2. ensure rights for disabled people
3. provide the best education for disabled people
4. provide opportunities in employment and economic development for disabled people
5. foster leadership by disabled people
6. foster an aware and responsive public service
7. create long-term support systems centred on the individual
8. support quality living in the community for disabled people
9. support lifestyle choices, recreation and culture for disabled people
10. collect and use relevant information about disabled people and disability issues
11. promote participation of disabled Maori
12. promote participation of disabled Pacific peoples
13. enable disabled children and youth to lead full and active lives
14. promote participation of disabled women in order to improve their quality of life
15. value families, whenau and people providing ongoing.

(Ministry of Health 2002, p 3)

Beside the vision twelve key Government departments were charged with developing work plans ready for implementation by the middle of 2002. Work plans had to reflect department's priorities and those, which were aligned with the strategy's vision. A number of work plans have been released. The Ministry of Health work plan has a description of a number of key achievement areas with desired outcomes, time frames and what progress has been made to meet the outcomes. An example from the Ministry of Health is listed below:

Description: The Ministry will promote that all strategies and final reports consider the needs of disabled people. Where appropriate Sector Reference Groups will include a disabled person to ensure that the view of disabled people are reflected at a strategic level.

Desired Outcome: The Ministry's staff will be more aware of the different needs of disabled people.

Quality Measures and Time Frames: All existing and future Sector Reference Groups will include at least one disabled person (where appropriate) on the group. To be implemented by 31 October 2001. All future strategies and final reports will consider the needs of disabled people. To be implemented by 31 December 2001.

Progress: Sector Reference Groups now include a person with a disability where appropriate. Examples of this are: the Youth Health Strategy appointed a disabled person to their sector reference group and the Health and Disability work force advisory committee now has a member representing a disability perspective. (Ministry of Health Work Plan 2002)

As noted one of the key objectives was to foster leadership by disabled people and this objective is looked in depth in the next section.

The Partnership

One group that the funding organisations (Government Departments, NGOs etc.) were not hearing from was disabled people themselves. As stated earlier DPA and another organisation The Association for Blind Citizens (ABC) were the exceptions in providing the voice for disabled people. In 1991 the Northern Locality of the then Health Funding Association (HFA), now the Northern Locality Disability Issues Directorate Ministry of Health, realised that the voice of disabled people was missing. This occurred when the HFA went out to tender for a service and on the selection panel were personnel representing locality, financial, Maori and Pacific people but no one representing disabled people.

From this discovery, the HFA embarked on a partnership initiative between themselves and the Auckland region of DPA. Immediately tensions started to develop when existing organisations felt under threat by the new kids on the block, and other disability organisations and groups wanted to have the same level of participation within the HFA. One of the major issues that were raised by opposing groups was that of representation. Did DPA represent parents and disabled people who had no verbal communication skills? Shakespeare (1993, 1994) has written extensively on the role of disabled people in voluntary agencies and the issues that arise.

Participants of the DPA/HFA partnership were a mix of disability types which meant that individual needs had to be put aside and a common focus needed to be developed very quickly. Patston (2002) sums up the issues succinctly:

> Through these challenges we have retained a certain unity by having a shared vision of a better future for disabled people. Even though we were often not seen as leaders because of society's disabling perceptions, we considered our most important job was to ensure the continuity of the voice of disabled people.

It could be added that the voice of the disabled that needed to be heard was a united voice, not one that was divided. Also the small number of people who were involved in the development of the partnership and the total number of people within DPA were further tensions that needed to be managed.

One issue that arose was how to fund the partnership. The HFA were unable to fund individuals and so a joint venture was signed between NZCCS and the HFA, with a Memorandum of Understanding signed between NZCCS and DPA. Going on at the same time was a Government initiative "The New Zealand Disability Strategy". What the HFA did not want was a local project upstaging a national consultation process.

Two projects were undertaken by the partnership in the initial stages, the Kids Vision and YPD (a project looking at young people with a disability aged between 16 - 64 who were inappropriately placed in rest homes and/or private hospitals). Each project was assigned a leader from DPA and the HFA, whose role it was to lead respective processes.

With the partnership bedding down and producing results it was acknowledged that another way to fund this project had to be found from the HFA and DPA perspectives. DPA being a national organisation meant that the Auckland region could not sign the contract, yet the Ministry by this stage only wanted a local initiative. One-way forward was to start "yet another" grouping that represented disabled people in the Auckland area - Ripple Trust.

DEAS (Disability Empowerment Advocacy and Support)

A number of other groups were forming similar initiatives with the Ministry of Health and it was good sense to bring these organisations together to form a type of collective. This collective was known as DEAS (Disability Empowerment Advocacy and Support) and consisted of Te Roopu Waiora (Maori), Pacific Information Advice and Support Services (PIASS Trust), Parent and Family Resource Centre (PFRC, representing parents) and finally Ripple Trust (a contract with Refugees was also a part of Ripple Trust). Each group had individual governance while also creating a shared management and chairs group. Not only were groups having to find a way work with their own, but also needing to find a way for the groups to work together.

Suddenly individual organisations had to realise, as O'Brien (1997) states, "outcomes will not be determined by definition of their purpose alone but by the paradigm that the service provider has of the characteristics of its service user group" (p 66). In other words the paradigm that the DEAS is operating in, is one of partnership and therefore results will not only reflect the individual group but also the "collective". As the Ministry of Health cannot be a fund-holder, the possession of the funds for the projects must be with one of the groups; therefore each group has a turn of being "in control".

Two projects are currently underway: (1) Community re-integration project which is the next stage of the YPD project and is looking at other initiatives to support disabled people who currently reside in rest homes and or private hospitals; and (2) the VIP project (Valued, Included and Participating) and is currently being led by Ripple Trust. This project aims to implement the New Zealand Disability Strategy and is looking at how to increase the capacity of disabled people within the community.

What has occurred with the initial development of the partnership, leading on to DEAS, follows the pattern that Shaw (1996) describes: "Residents were entirely unorganized, organizers were energetic, but inexperienced, and our opponents were multinational hotel corporations ... how could we succeed ... the answer lay in tactical activism (p 9)." DPA did not decide to take on the Health Funding Authority overnight. What has been achieved was done by breaking down the barriers into small achievable projects that showed the value of working with disabled people rather than against them. Also what was achieved was done so by a small number of people who were committed to the outcome, sharing a common goal focussed on societal rather than individual change.

It was not all rosy however and a number of people who started with the development struggled at times, and with small numbers of disabled people it was easy for opponents to pick people off. But what was important was that if one person moved on another one person took the vacant place. Prior to attending this conference a joint meeting took place attended by at 25 people. This may still seem to be small numbers, but when the ideas were first raised there were only two people then five, then seven and it built from there. One of the goals of the partnership was capacity building of disabled people and stakeholders, which has been achieved.

Conclusion

What this paper has shown is that there is a hierarchy within the disability sector in New Zealand, as pointed out the level of support in some situations depends on how the disability was acquired. What the partnership and DEAS has shown is that with a single focus, a diverse group can work together to achieve a common purpose. However the goal in the coming months and years is to stay committed and focussed.

While there are larger numbers of people committed to the process they still represent five different organisations. The next phase of the project and probably the hardest, is to keep the groups focussed on issues and not have individuals go off on diverse tangents. The other issue is to find the next generation of disabled people. Some of the current participants have been in this type of role for over 20 years and while they still want to make a difference (and are) it is now up to the next generation of disabled people to continue the struggle.

The final word on the development of the partnership leading on to the DEAS is left to Patston (2002):

> The Partnership between disabled people and the Ministry of Health was, and continues to be, one that left behind the tokenism of consultation for the involvement of disabled people through daily participation in decision-making. To do this required us to build alliances both within and between the two groups, while working to realise a shared vision of a better future for disabled people. This couldn't have happened without the fostering of personal and professional relationships between people inside and outside the bureaucracy.

The battle certainly has not been won but so much more can be achieved by a small number of committed people rather than a large fragmented crowd.

Ka Kite Ono (Go well and we will meet again)

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