

COLLABORATION IN THE PROCESS OF LEGISLATIVE LOBBYING:

A STUDY OF A DISABLED PEOPLES ORGANISATION LOBBYING FOR CHANGE IN

NEW ZEALAND

1989-1993

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Abstract

This thesis examines lobbying from the disabled people's organisation Disabled Persons Assembly (DPA) NZ from 1989 until 1993. It explores how the organisation conducted lobbying activities with respect to two pieces of New Zealand legislation with constitutional significance: The New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993.

This thesis places the plight of minority groups within the political process squarely under the research microscope and asks: what factors explain the different outcomes to the DPA's lobbying efforts to the Bill of Rights in 1990 and the Human Rights Act in 1993?

More specifically it examines the DPA's decision to collaborate with the New Zealand Aids Foundation (AF) during the 1993 Human Rights Act campaign. Collaboration with the AF was a controversial decision that resulted in heated discussions within DPA. Some members were concerned about the political risks of aligning with the AF. DPA leadership however saw a possibility for broad human rights legislation, and took the decision to collaborate. They were convinced that collaboration would bring benefits in the form of greater resources, access to Parliament and better relationships with the media which would all lead to an enhanced capacity to make the case to the public.

The thesis argues that by working with the AF, DPA was able to change its lobbying narrative from one solely focussed upon disability rights to one that broadened out to broader human rights protections. DPA was not positioning itself as a minority group arguing for narrow exceptions to existing legislation, a tactic it had pursued in previous campaigns. The campaign proved successful, gaining support from MP's, as the Human Rights Act was perceived to have public support.

The thesis also shows that to understand DPA's successful strategy it needs to be seen in the context of a failed effort from a previous campaign. DPA's campaign to lobby for the 1993 Human Rights Act began from the point of an unsuccessful fight to have disability rights included in the 1990 Bill of Rights. DPA was, in effect, 'locked in' to fighting the 1993 campaign from that point.

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Chapter 1 Introduction

Lobbying is generally understood in political science as an expression of the democratic process, as is the study of how minority groups seek to actively represent their communities within the political process. There is a large literature on the political activity of minority and interest groups in New Zealand,¹ but there have been few studies exploring how disability groups participate in the lobbying process.² This thesis looks at disability rights groups' participation in the lobbying process. It focuses on one specific coalition, Disabled Persons Assembly (DPA) NZ, a pan disability umbrella group representing all impairment types and how it worked to advance its agenda around one legislative event, the passage of the Human Rights Act 1993. The thesis looks at DPA's struggle to get an expanded definition of disability included into the 1993 Act. It asks the question, why did Disabled Persons Assembly NZ choose a potentially more difficult lobbying path in 1993 by partnering with the AF when the possibility of legislative success was available by advocating for a disability specific provision?

The purpose of this thesis is to find answers to this very basic question. Why did DPA take a big risk, upon such a big piece of legislation, when they had so much to lose? To find answers, the thesis initially looks to the history of the disability movement in New Zealand to examine why the movement developed as it did, and how it led to the creation of DPA in 1983.

¹ See Cleveland, L. 1972. *The Anatomy of Influence: Pressure Groups and Politics in New Zealand*. Hicks Smith and Sons. Wellington, Owens, J, L (1992) "Pressure group operation in theory and practice: a theoretical evaluation of the effect of New Zealand abortion-related pressure groups on legislative change" MA (Hons) Political Science VUW, Buckle, S, M(2009) "Pressure Groups Under MMP: a Study of Behaviour and Influence" MA Political Science VUW

² Sullivan, M & Munford, R (1998) "The Articulation of Theory and Practice: critique and resistance in Aotearoa New Zealand" *Disability & Society* Vol.13 No.2,p.194, Sullivan, M. J. (2001). *Disabled people and the politics of partnership in Aotearoa New Zealand*. In L. Barton (Ed.) (Eds.). *Disability, politics and the struggle for change* (pp. 93-109). London, UK: David Fulton Publishers. Tennant, M, (1996) "Disability in New Zealand: a historical survey" *NZJDS*, p.28

From the creation of the Disabled Persons Assembly, the thesis will outline the two lobbying efforts by DPA which are most well recognised. First, the lobbying to include disability protection within the Bill of Rights 1990 and second, lobbying to include a disability clause within the Human Rights Act 1993. Both pieces of legislation were constitutionally significant and both received lobbying from a wide cross section of the community. By outlining the two instances of lobbying by DPA conclusions will be drawn as to what factors determined a successful lobbying campaign.

The thesis will argue that three factors distinguished the two lobbying efforts. First, collaboration, second, issue framing, and third, path dependency.

By collaborating with the AF, on the issue of discrimination, an issue that both organisations' members had shared experiences of within society, DPA was able to work with a group which brought skills in the area of lobbying that it did not possess. The Aids Foundation had access to Ministers and to key officials.³ It also had a nationwide database of activists in the community and a positive relationship with the media. DPA benefitted from the collaboration with the AF in terms of gaining access to key Ministers building a positive relationship with the media by which to put important messages to the public. The collaboration with the AF sits at the heart of the thesis. The decision to collaborate however arguably made DPA's lobbying effort harder in 1993.

The fact that DPA was able to frame the issue of disability as a broader human rights concern in the second lobbying effort in 1993 was instrumental in its success. Prior to 1993 DPA had experienced difficulties and resistance when lobbying Members of Parliament about legislation that affected disabled people. As a constituency, the disability community

³ Contacts and access to Ministers were developed over the passage of the Homosexual Law Reform Bill 1986

represented a community with very little 'political clout'. DPA members ⁴ reported having their concerns dismissed when lobbying for the inclusion of a protection based upon disability upon its own.

DPA's unsuccessful lobbying campaign in 1990 made the 1993 Human Rights Act campaign even more important. As an organisation DPA experienced failure in the lobbying process, and knew the consequences of a repeated lobbying failure. A sense of desperation pervaded the lobbying effort in 1993 with lobbyists from DPA understanding that the 1993 legislation could be the last chance to secure protections for people with disabilities.

Methodology

This thesis focuses on political lobbying by the disability community in New Zealand. There has not been a large amount of academic writing devoted to this topic and this thesis is an attempt to begin to address that gap. The thesis focuses upon the passage of the Human Rights Act 1993 and the lobbying around its adoption. To demonstrate the pressures and constraints that DPA were subject to in the lead up to the 1993 campaign the 1990 Bill of Rights campaign will be examined as example of an unsuccessful lobbying effort and also considered as the foundation for the successful 1993 campaign.

A set of 7 interviews were conducted with the key participants within the New Zealand disability community and the New Zealand Aids community who were politically active and lobbied for legislative change during the period 1989 to 1993. Members of the disability

⁴ Pers Comm. Dave Henderson 21/3/12

community who worked in the office of the Associate Minister of Health's office, Katherine O'Reagan, (and who therefore could not actively lobby), but were none the less supportive of the reform were also interviewed. These interviews provide part of the primary data set for the thesis. The remaining primary data set is made up of Hansard records of the passage of both the Bill of Rights 1990 as well as the Human Rights Act 1993, all email and other records that the National Archives has released from the Ministry of Justice and Crown Law pertaining to the National Impact statements of the Bill of Rights Act 1990 and the Human Rights Act 1993 in addition records from National Archives relating to Disabled Persons Assembly lobbying efforts to government and communication between DPA and government ministers between 1989 and 1993.

As Stake argues, case study research is about "exploring cases in a qualitative, naturalistic, holistic, ethnographic ... fashion rather than breaking cases down into quantifiable variables."⁵ Using a case-study approach as a basis for comparison, the thesis contrasts the legislative campaigns of DPA in 1990 and in 1993. It allows the researcher to pay attention to complex processes by which events unfold, and from which causal explanations can be deduced.⁶ This thesis uses a process of inductive reasoning to make reasonable estimations in determining what factors led to the failed 1990 Bill of Rights lobbying campaign by DPA and a successful effort in 1993.

I argue that in the 1990 campaign the factors that led to an unsuccessful lobbying effort included coming up against a policy elite who had a different vision for the Bill than DPA's,

⁵ Stake, R (1995) *The Art of Case Study Research*. London, Sage, p. XV

⁶ David, M & Sutton, C (2011) *Social Research: An Introduction* 2nd Ed London, Sage. pg.173

the unfavourable relationship DPA had with Parliament and the fact that DPA presented its lobbying as a disability-specific issue. Conversely in 1993, the DPA was able, by collaborating with the AF, to navigate the institution of Parliament successfully. Key members of Parliament were identified, meetings set up and the case for broad legislation was argued. In concert with the AF, DPA was able to re-define a narrative that had been focused narrowly on disability to a broader narrative that focused on human rights. DPA was able to move from narrow technical issues relating specifically to disability, to broad issues that affected many groups in society. The DPA's interaction with the AF also brought a new positive experience with the media. In past campaigns DPA had a fractious relationship with the media, viewing the fourth estate with scepticism and at times adopting a 'siege mentality'. Working with AF allowed DPA to build positive relationships with the media and through that generate greater support from the public.

The key informants who tell the stories of the lobbying from 1989 until 1993 were chosen for their ability to convey their experiences and their personal involvement with the passage of either the Bill of Rights Act 1990 or the Human Rights Act 1993 or both. Key participants include Dave Henderson, Chief Executive of DPA and Anne Hawker, Chair of the Board of DPA. Both worked for Disabled Persons Assembly NZ during the passage of the Bill of Rights Act 1990 and Human Rights Act 1993. Wendi Wicks was Wellington secretary of DPA during the passage of the Human Rights Act. Robyn Hunt, worked for the State Services Commission, and had many roles within the public sector, during the passage of both pieces of legislation, and was an active member of DPA. Paul Curry was a foundation member of DPA, worked for the Ministry of Health as the Manager of Disability Support Services at the time of the passage of both pieces of legislation, Curry was drafted into Katherine O'Reagan's Ministerial office to

provide expert advice on matters relating to disability policy during the passage of the Human Rights Act. Finally, Charles Chauvel worked for the AF as a trustee and Board member and was also seconded into Katherine O'Reagan's office as a volunteer to provide expert advice on issues relating to HIV and Aids.⁷

Interviewing members of the disability community presented several challenges for me as interviewer and researcher. First, I identify as having lived experience of disability, and have been employed by DPA, my research subject, I know several of my interview subjects in a professional capacity. Second, I brought a large volume of pre-existing knowledge about the subject matter of my research question, in addition to my own personal experience of disability into the interview process. In order to address these potential obstacles to objectivity I made a determined effort not to let personal beliefs and experiences influence the interview process. I have tried to be always reflective and conscious of these factors and not to let my own subjectivity interfere with the data gathered through interviews with key informants.

Thesis Structure

The representation in Parliament by disabled people on issues relating to disabled people has not been a common feature in the New Zealand political landscape. People with disabilities have not actively represented or lobbied Parliamentarians historically. This thesis focuses upon the two most well known occasions of lobbying by the disabled people's organisation (DPA) NZ, when it lobbied for the inclusion of a disability clause within section 19, the right to

⁷Unfortunately, although numerous attempts were made to interview (in person and via email) Sir Sir Geoffrey Palmer regarding his involvement with DPA during the passage of the New Zealand Bill of Rights 1990, all requests for interviews were declined.

freedom from discrimination clause, of the Bill of Rights Bill 1990 as well as lobbying with the AF to insert disability and sexual orientation as grounds of illegal discrimination within the Human Rights Bill 1993.

Chapter Two outlines the foundation of all legislation that relates to disability, the United Nations International Year for Disabled People 1982 and the resulting UN Decade for the Disabled 1983-92. The UN Decade produced the United Nations Standard Rules on the Equalisation of Opportunity for Persons with Disabilities (UNSR) 1993 which are the blueprint for all member nations on how to conduct disability policy. This chapter focuses upon Rule 15 of UNSR which sets out the process by which each member state is obliged to pass legislation protecting the rights of disabled people.

The chapter briefly outlines disability discrimination legislation passed in three jurisdictions between 1990 and 1995, in the United States, Australia, and the United Kingdom, and the role of disability rights groups in the passage of each piece of legislation. By outlining the content of the legislation and the roles of disability lobbying groups in the passage of each piece of legislation the actions of New Zealand's DPA can be placed into a comparative context. Chapter Three provides a history of the disability movement in New Zealand from 1981 till 1990. This period was chosen as it encompasses the creation of DPA in 1983 and it also witnesses the beginnings of a change within the New Zealand disability movement. Prior to 1981 disability organisations were largely run by non-disabled people, parents of disabled people, doctors, and charitably minded people. During the period 1980 to 1990 a rising of consciousness within the disability community developed whereby disabled people no longer saw it as acceptable to have organisations lead and staffed by non-disabled people. As a result of this sea-change in consciousness the leadership within many disability organisations within New Zealand and worldwide changed hands from non-disabled to disabled people.

Chapter Four connects the previous ideas of an up-swell in consciousness within the disability community to the decision by DPA to lobby for the inclusion of disability as ground from which disabled people could seek protection from discrimination. The lobbying by DPA was the first major piece of lobbying by a disabled persons organisation in New Zealand. The DPA would encounter several obstacles to success including a determined principal sponsor of the Bill who had a particular view of the purpose of the Bill, a lack of contacts within the Parliament, reluctance by the Members of Parliament to listen, and to have sympathy for disability related issues when lobbied as exclusively disability issues.

Chapter Five outlines the next lobbying attempt by DPA in 1992/3 during the passage of the Human Rights Act. The chapter starts with an initial legislative scuffle when DPA worked with the Human Rights Commission to argue against the insurance lobby that disability should not be granted an exemption from the Act on the basis of it being a legal basis for discrimination. The chapter then moves on to the main fight, the lobbying that DPA and the AF entered into to gain a disability clause as a ground of illegal discrimination within the Act.

The chapter follows the internal discussions, within DPA over whether to collaborate with the AF in the lobbying, as well as the lobbying within Parliament from the participants within the Ministerial office. The campaign was successful with the disability amendment being passed into the Human Rights Act 1993. The chapter concludes with remarks over what distinguished the successful 1993 Human Rights campaign from the non successful Bill of Rights Act 1990 campaign.

This thesis does not pretend to provide a comprehensive study of the DPA (NZ). It focuses on the efforts that DPA engaged in from 1989 until 1993. This was a significant time period in DPA's history, culminating with the inclusion of the disability clause in the Human Rights Act

1993. The thesis draws conclusions that differentiate DPA's unsuccessful 1990 lobbying campaign from its successful 1993 campaign.

Chapter 2 Literature Review

Methods

Research for this thesis involved the use of a wide range of primary and secondary resources. Scholarly Literature for this study was accessed initially through searching PIAS and Proquest Central Databases. The intention of the searches was to limit material to the area of disability-specific lobbying in the jurisdictions of the United States, Australia and the United Kingdom. Searches for lobbying from within the United States provided large search results and academic commentary related to the passage of the Americans with Disability Act 1990 and the disability lobby's involvement in the passage of that Act, as did results from the United Kingdom relating to the involvement of the disability movement in the passage of the Disability Discrimination Act 1995. The least fruitful result in terms of search was the involvement of the Australian disability movement in the passage of the Disability Discrimination Act 1992.

This literature review has several limitations; first, it focused upon events from the mid twentieth century to the early twenty first century. Arguably the disability rights movement began before that point. Second, there are milestones that relate to the disability movement in New Zealand and the passage of the Human Rights Act 1993 that need to be considered, which occurred after 1995. Two such milestones include; the Accessible Bus litigation in 1995 as a result of the passage of the Human Rights Act. Disability Activists within New Zealand took Stagecoach, (a Wellington bus provider) before the Human Rights Review Tribunal (HRRT) to claim that the provider must make public transport accessible and the failure to do so was in breach of section.44 of the Human Rights Act.⁸ To support the claim the Human Rights

⁸ http://legislation.govt.nz/act/public/1993/0082/latest/DLM304621.html?search=ts_act_Bill+of+Rights+Act+1990_resel&p=1 accessed 16/8/12

Commission produced the report “The Accessible Journey”⁹ highlighting the plight of disabled public transport users and advocating potential solutions.

Second, in 1996 Statistics New Zealand was legally obligated, as a result of the passage of the Human Rights Act, to collect data upon the disability community. Prior to 1996 data was neither collected nor published within the Census.

Ethical approval was sought and received in December 2011 from the Victoria University University Human Ethics Committee to conduct interviews with nominated subjects. In order to achieve approval rational for approaching subject was provided as well as a list of intended interview subjects and interview question sheet.

Participants for interviewing who had experience of the disability rights community were recruited through an informal process. Email contact was made where by the intention to interview was stated and a research abstract was included along with an outline of the area of the research there participation would most greatly assist with a request to participate. All interviews were tap recorded with respondents given the option to have a transcript provided, only one accepted. Formal requests were sent to Charles Chauvel, Katherine O’Reagan and to Sir Geoffrey Palmer, with all declining but Charles Chauvel. A formal interview was conducted at the parliament offices of Charles Chauvel. At the conclusion of the interview, a request was made to see a draft of the thesis, this was complied with and alterations were made to characterisations made during the interview.

Documentary and Archival research

Several key documents were necessary for the completion of this study. First, submissions by DPA to the Justice and Law Reform select committees during the passage of

⁹ Human Rights Tribunal “The Accessible Journey” <http://www.hrc.co.nz/report2/index.html> accessed 16/8/12

both the Bill of Rights Act 1990 and the Human Rights Act 1993. Second, submissions by the insurance lobby, the Investment Savings & Insurance Association (ISI) to the Justice and Law Reform select committee during the passage of the Human Rights Act 1993. Third, Hansard speeches during the passage of both the Bill of Rights and the Human Rights Act. Fourth, documents received from the Human Rights Commission "Report Reviewing the Human Rights Commission Act 1977."¹⁰

All documents provided and data to complement the primary source material that the thesis is based upon, the set of interviews conducted with interview participants who participated in the passage of the Human Rights Act.

Case Study Selection

This thesis is not a comparative exercise, however is important to ground the New Zealand disability movement's experience of lobbying for legislative change within an international context. With this in mind three examples of international disability rights movements' involvement in the passage of legislative change will be outlined from which to help draw comparisons with the New Zealand experience. Three disability rights communities have been chosen for this study. First, the United States of America, second, Australia and third, Great Britain. There are several reasons for the selection of these three particular cases, they are as follows:

First, the disability movements within each country are strong. All represent movements that the New Zealand disability movement looks to for intellectual as well as tactical direction.

¹⁰ Review of the Human Rights Commission Act 1977 Report to the Minister of Justice Human Rights Commission, August, 1987

Second, while the legal systems differ in two of the three countries, each country shares a liberal democratic style of democracy. While Australia and the United States operate Federal systems, New Zealand, Australia, and Great Britain share a common law legal tradition. The United States of America does not operate a common law-based legal system.

The case study of Canada was considered carefully but rejected for the reason that there are not strong enough links between the disability movements in Canada and New Zealand. Canada would be a good match if comparing the legal and political systems of New Zealand and Canada however this is a study focussing upon the impact of disability movements upon the legislative system.

Lobbying: a theoretical backdrop

What does it mean to lobby? An answer to this question is necessary before moving on to questions of why the (DPA) decided not to lobby for a disability specific provision within the Human Rights Act 1993. And why DPA chose to adopt the tactics it did.

Milbraith offers a definition of lobbying, by asserting that:

“... lobbying is the simulation and transmission of a communication, by someone other than a citizen acting on his or her behalf, directed to a governmental decision maker with the hope of influencing his or her decision.”¹¹

Taking the position that lobbying is a form of communication, McGrath argues that the manner an issue is framed can define the problem as well as the outcome. McGrath uses the phrase ‘someone other than a citizen’ to distinguish people who lobby from what he would imagine as citizens, the act of lobbying in McGrath’s mind takes one away from being a ‘citizen’.

McGrath uses the 1995 Shell Oil Brent Spar oil rig platform incident to illustrate. The Greenpeace activists’ key messages in response to the incident focussed upon the non-acceptability of Shell’s practice, arguing “no one had been allowed to dump their rusty old car in the neighbourhood pond for 30 years”¹²

¹¹ Millbraith, L.W. (1963) *The Washington Lobbyists*, (RAND, McNally: Chicago, Ill) in McGrath, C (2007) “Framing lobbying messages: defining and communicating political issues persuasively” *Journal of Public Affairs* vol 7 p.269-280,276

¹² McGrath, C (2007) “Framing lobbying messages: defining and communicating political issues persuasively” *Journal of Public Affairs* vol 7 p.269-280,276

Within society there might be citizens that would wish to 'park their rusty car in the neighbourhood pond for 30 years' By taking a position and advocating that position to governmental decision makers McGrath is demonstrating the effect of lobbying.

Disability activists within New Zealand, during lobbying efforts prior to the Human Rights Bill 1993, defined disability in narrow terms, narrowing the debate to physical access, transport, housing, employment. During the 1993 campaign that definition was widened to encompass broader discrimination experienced by many within society. Prior to the 1993 campaign the manner in which disability activists defined the problem limited the response that could be made by decision makers as the issue was framed as affecting a limited number of the community with little political power. In the 1993 campaign by framing the issue in terms of discrimination affecting many, DPA broadened the appeal to decision makers and to the public.

Comments by senior Labour politician, the Hon. Dr Michael Cullen in the New Zealand Parliament during the third reading of the Human Rights Bill indicate that Parliament would have passed such a provision:

“... if we could have separated the issue of disabilities it could have been dealt with quickly” ¹³

Instead DPA chose to pursue a much more challenging, less logical legislative path. If DPA was trying to maximise their chances of success in securing a legislative victory the option they chose seems to challenge a rational approach.

¹³Human Rights Bill 27 July 1993, (Hansard, 16973)

Mancur Olson's, 'The logic of Collective Action' analysed the paradox of participation which raises the proposition that rational actors will not participate in collective action in order to achieve collective goals. Immediately the DPA campaign raises empirical challenges to Olson's proposition. DPA acted in concert with the AF, lobbying to achieve a collective goal, the passage of a piece of legislation. A theoretical explanation must be found that explains the empirical behaviour. Seeming to confirm this empirical challenge to theory, Ordeshook comments that "rational choice scholarship does not rest on a readily identifiable set of empirical successes."¹⁴ In support of this conclusion McKelvey and Rosenthal note with relation to game theory that rational choice has only made a substantial impact upon political science at a conceptual level, and that only rarely has it led to "rigorous empirical analysis of real world behaviour."¹⁵

The greatest challenges to rational choice have been directed toward the assumptions of human psychology and rationality. The disability movement literature illustrates that group identity can have an impact upon overall group unity. Galvin explains:

"the need for unity at both an individual and group level is understandable and cannot be easily resolved ... how can we build movements based upon shared experiences without claiming some sense of unity ... it is the recognition of my pain or oppression in someone else that allows me to deny the idiosyncratic nature of my experience ... and to deny my guilt at being different from the 'norm'"¹⁶

¹⁴ Ordeshook, P.C. Game theory and political theory : an introduction, Cambridge ; New York : Cambridge University Press, 1986.

¹⁵ McKelvey, R & Rosenthal, H. 1978. "N -Person Cooperative Game Theory and Spatial Models of Politics: Empirical Analysis of Electoral Coalitions in France." In Game Theory and Political Science, P. Ordeshook, editor. New York: NYU Press,

¹⁶ Galvin, R, (2003) The paradox of disability culture: the need to combine versus the imperative to let go. Disability & Society Vol. 18 no. 5 p.675-690, 684

Here Galvin argues that groups made up of different identities seek unity in collective experience, or collective suffering, while at the same time members wish to have space for their own individual experience and identity. These groups according to Galvin find collective unity difficult. This was and is reflective of the experience of DPA, a group made up from many different individual people with disability, each who share the commonality of being viewed as disabled by the able-bodied world, while each member is at a different stage of their disablement journey, affecting how they see themselves, others and the wider world.

The second challenge to rational choice comes from its inability to fully explain political action.

Whiteley explains:

“... a purely rational actor model provides an incomplete explanation of political action; important motives for participation exist in high cost types of activities, which are inconsistent with the standard rational actor model ... activists are motivated by expressive concerns and by a sense of collective efficacy, both of which are inconsistent with this model.”¹⁷

The disability movement demonstrates that within a group of people multiple ways of viewing the challenge to secure legislative protection exist, such as through the Human Rights Act 1993. Beckett argues:

“...not all disabled people seek recognition on the basis of difference What disabled people do seek is to be treated as equal persons.”¹⁸

Beckett uses the UK disability community within his example, commenting that there is a diversity of opinion regarding the best strategy to pursue. Within Beckett’s nuanced

¹⁷ Whiteley, P (1995) “Rational Choice and Political Participation – Evaluating the Debate” *Political Research Quarterly* vol.48 no.1, p.211-233,227

¹⁸ Beckett, A.E. (2006) “Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement” *Citizenship Studies*, vol.9 no.4 p.417

observation sits the comment that while the disability community may be divided along identity lines, there is unity about the goal of recognition. Young highlights a particular area of concern within the area of identity, “individuals maybe inaccurately labelled as ‘different’ not only by dominant “outsiders” but also by dominant voices internal to the group.”¹⁹

This comment by Young points to larger debates about disability preference and ranking within the disability community,²⁰ the point that disabled people face labelling and challenges to identity from within the disability community as well as from society is well made by Young.

This larger point has relevance to the explanation of political action within disability groups. Many voices exist regarding strategy. Disability groups must work through the internal debates, overcome pre-existing prejudices when deciding to work with other groups that share a similar discrimination experience.

Why do organisations lobby?

This seems like an obvious question but one that must be answered before continuing further. It is important to state that there are divergent ideas within the discipline of political science as to why organisations lobby. An organisational approach to lobbying focuses upon the design and management of individual organisations involved in lobbying activities. Both micro and macro approaches to the organisation have been investigated. Macro approaches investigate the impact of environmental factors upon organisational behaviour. For greater

¹⁹ Young, I.M. (1990) *Justice and the Politics of Difference* (Princeton, Princeton University Press) in Beckett, A.E. (2006) “Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement” *Citizenship Studies*, vol.9 no.4 p.417

²⁰ Deal, M (2003) “Disabled people's attitudes toward other impairment groups: a hierarchy of impairments” *Disability & Society*, vol. 18 no.7

explanation of this approach the work of Scott, Hannan, Freeman and Aldrich is noteworthy.

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Both Truman and Dahl seek to understand why organisations lobby. The authors begin with defining lobbying as the process of “like minded individuals coming together in response to disturbances in the policy environment.”²²

This definition leaves open several gaps, first, it constrains the view of the lobby group to those that have similar positions on a single issue, and it confines lobbying as a response to a threat, or disturbance. Second, the definition does not account for inequality of resources, or inequality of access, at the institutional level or physical level, and third, it presumes that there are only a few groups that are without any means of pursuing influence.

Two institutional issues that restrain the ability of disability groups to lobby need to be outlined. First, groups that register as having charitable status in New Zealand are currently prevented by section 5 of the Charities Act 2005 from taking part in advocacy or lobbying.²³ This creates an institutional barrier to advocacy or lobbying for organisations which are charitable status dependant or whose funding is dependent upon donations. Organisations such as the Crippled Children’s Society (now CCS Disability Action) are prevented from taking part in lobbying while they have charitable status.²⁴ Many organisations within the disability, health, poverty, Maori and Pasifika communities are currently prevented from lobbying due to their charity status.

Another significant obstacle to disability groups political representation is making material that is under investigation within select committee accessible. This represents both an

²¹ Scott, R,W Institutions and Organization (Thousand Oaks, CA: Sage Publications, 2001); Hannan, MT and Freeman J, Organizational Ecology (Cambridge: Harvard University Press, 1989); Aldrich H,E, Organizations Evolving (London: Sage Publications, 1999)

²² Dahl, R.E Who Governs? (New Haven: Yale University Press, 1961); David B. Truman, The Governmental Process (New York: Alfred A. Knopf, 1951).

²³ See section 5 (3) Charities Act 2005

²⁴ Charities Commission v Greenpeace [2010] CIV-2010-485-829

institutional and a physical barrier to representation. The New Zealand Parliament states that not all documents are available in accessible format from the main e-government website,²⁵ by this very fact people with visual and intellectual disabilities cannot access the material from the select committee system.

Both Truman and Dahl's definition of lobbying has application to the DPA and the AF situation after the lobbying to include disability into the Bill of Rights 1990. Both had experienced a disturbance within the policy environment when it was made clear to both organisations after the 1990 campaign that an expanded disability clause would not be included within the 1990 Bill. Both organisations, despite differences within the disability movement over whether to partner with the AF, were united upon the goal that legislative protection was necessary.

Collaboration

Mertus points out that that groups such as the disability community, who are defined by their identity, have chosen to adopt traditionally based human rights strategies.²⁶ Rohlinger points to internal obstacles that prevent organisations from controlling their relationship with the media. Internal obstacles include such aspects as: limited resources and organisational identity leading to an inability to deal with journalists and the wider political environment, 'siege mentality.'²⁷

External obstacles which may be faced include: opposition or countermovement, an oppositional groups counter frame and the mass media taking an active position on the issue itself.²⁸

²⁵ <http://www.parliament.nz/en-NZ/Accessibility/2/7/5/275e6c9d1738447ea8b76ff811a4f3e3.htm>

²⁶ Mertus, J (2007) "The Rejection of Human Rights Framings: The Case of LGBT Advocacy in the US" *Human Rights Quarterly* Vol.29No. 4 p.1037

²⁷ Rohlinger, D.A. (2002) "Framing the Abortion Debate: Organisational Resources, Media Strategies, and Movement-Countermovement Dynamics" *Sociological Quarterly* Vol.43 No.4 p.481

²⁸ *Ibid* at 482

The decision to pursue broad human rights strategies results in disability groups having to look for partners in lobbying to broaden out their political appeal. During the passage of the Americans with Disabilities Act 1990, debate focussed upon extending the disability definition to include people with HIV/Aids. The definition of disability within the ADA adopted by the US Congress had pre-existed from the Rehabilitation Act 1973. Opposition to its inclusion gathered, formally opposition took the form of the 'Chapman Amendment' which proposed denying coverage under ADA to all persons with HIV. Opposition came from the National Restaurant Association and its allies. The Consortium for Citizens with Disabilities (CCD) combined with broader public health agencies and several unions lobbied to stop the Chapman Amendment. The coalition lost an initial vote in the Congress but prevailed in the final Congressional vote to have the Amendment removed from the final Act.²⁹ This collaboration by the CCD, by Unions and public health groups indicates that when groups feel an issue affects all equally, collaboration will naturally occur around an 'issue of importance'.

Kollman's assertion that 'public opinion matters'³⁰ has relevance when politicians and officials are assessing the merits of a policy proposal. If a policy proposal is presented as affecting many different groups, a Minister will look upon it with different eyes. In the case of the DPA and the AF the same holds true. During the 1990 campaign DPA presented disability as an issue affecting only disabled people when lobbying in front of select committees. In 1990 DPA did not have access to Ministers, and did not work with other NGOs within areas of interest. The result of this single-issue focus was that DPA was unsuccessful in its lobbying in 1990.

²⁹ McGuire, J.M (1994) "Organizing from diversity in the name of community: lessons from the disability civil rights movement." *Policy Studies Journal* 22.1

³⁰ Kollman, K *Outside Lobbying Public Opinion and Interest Group Strategies*, Princeton University Press, 1998,

Path Dependencies

The outcome of the lobbying by DPA in the 1990 Bill of Rights campaign was a resounding defeat. Disability was left out of the Bill as a ground of discrimination that was afforded protection under the freedom from discrimination clause. DPA knew as an organisation they had to secure protection for disabled people and that if they failed again, a chance to gain legislative protection may not present itself for some time. Both DPA and the AF were determined that the failure of the 1990 campaign would spark a successful campaign in the Human Rights Bill campaign. It was an opportunity that both organisations had to secure a legislative victory. Raadschadlers describes path dependency as “a string of related events, as causality in retrospect.”³¹

In this respect the successful lobbying effort by both DPA and the AF to secure an expanded disability definition with a sexual orientation definition included in the Human Rights Act 1993 was originated by DPA’s unsuccessful lobbying effort previously lobbying for disability to be included into the Bill of Rights 1990. However, this explanation is not convincing in that it does not help to explain the events that occurred leading to a successful lobbying effort in 1993.

A key issue in path dependence is perspective, placing the analysis of policy development within the macro setting. Looking at policy analysis as a whole, Kay argues that from a more fine-grained perspective whether an issue is locked in or whether it is capable of being reformed becomes relevant.³² For DPA, from the time of their legislative defeat in 1990 the

³¹ Raadschadlers, J.C.N. (1998) “Evolution, Institution Analysis and Path Dependency: an administrative-history perspective on fashionable approaches and perspectives” *International Review of Administrative Sciences*. p. 576

³² Kay, A(2006) *The Dynamics of Public Policy: Theory and Evidence*, Northampton, MA , Edward Elgar, p.38

organisation was always going to mount another campaign in 1993, DPA was, in effect, locked in.

The lobbying that DPA engaged in the 1993 campaign by joining forces with the AF changed the wider policy environment. This joining of forces redistributed power, as the AF brought with it greater resources and hence power to the DPA in the lobbying process.

Objectives

What are the objectives of an organisation seeking to lobby? An organisation can attempt to enter into a transactional lobbying relationship whereby it seeks to influence legislation or stop legislation from being passed. To follow this path would be to adopt the transactional model of lobbying. By adopting a transactional approach, groups can build relationships with institutions which over time will result in policy directed toward their cause or interest.

Stone puts forward a two level campaign as a model for groups to follow. First, groups must establish a powerbase in Parliament, and second, groups must be supported by mass public activities.³³ On contentious issues, such as abortion or HIV, the lobbying of MPs becomes important as legislation is voted upon conscience lines, therefore the effective lobbying of MPs becomes crucial. In addition, a group's ability to win the battle of public perception largely fought through the media can often determine the success of a legislative campaign. DPA knew that collaborating with the AF would bring them an established powerbase within Parliament. Activists within the AF brought campaign experience from previous successful

³³ Stone, R (1977) "Group Struggle in a Value Field: The Comparative Performance of New Zealand Pressure Groups on the Question of Abortion, 1970-1975" Political Science Vol. 29 p.145

legislative campaigns such as the Homosexual Law Reform Bill in 1986. Activists brought knowledge about which Members were 'approachable' and which were not.

The AF had established a positive relationship with the media and used the media as a vehicle to promote a positive identity and to portray issues. DPA had a suspicious view of the media stemming from the 1981 International Year of Disabled People which provided mixed results in terms of media portrayal of people with disabilities.

Banchoff argues that democratic constitutions, which are constructed from individual pieces of legislation, are essentially normative frameworks that mitigate against radical policy departures, promoting incremental change. For Banchoff, a conservative bias can be expected around values driven-issues for the reason that defenders of the status quo can more easily associate their policy framework with an existing constitutional legacy,³⁴ than the fact that constitutions embody traditional values.

The conservatism that Banchoff describes created the possibility for the disability amendment to the Human Rights Act 1993. The passage of the disability amendment into the Human Rights Act 1993 was the result of incremental change. From 1971 to 1993 as Human Rights legislation within New Zealand was continually reviewed, the definition of disability within other legislation was widened at each review. The passage of the disability amendment into the Human Rights Act 1993 was made possible by the previous policy work that had paved the way, carving out new grounds of illegal discrimination. At the forefront of this policy work was the Human Rights Commission Report 1988 which reviewed the Human Rights Commission Act 1977. This report stated that the failure to include discrimination on the

³⁴ Banchoff, T (2005) "Path Dependence And Value-Driven Issues: The Comparative Politics Of Stem Cell Research" *World Politics*; 57, 2; p.209

ground of disability within the 1977 Act was “the most important deficiency” to the legislation.³⁵ The report shaped the debate in the lead up to the 1992 lobbying campaign; Labour Justice Minister Bill Jeffries refused to implement the disability discrimination clause recommendation when a 1989 amendment came before the House. This in turn shaped the disability community’s response heading toward the fight for inclusion of ‘disability’ into section 19 of the Bill of Rights, which provides a freedom from discrimination

The non-successful 1990 legislative attempt placed DPA at somewhat of a crossroads. DPA’s Dave Henderson confirms that within the disability community there was a real fear that the 1993 legislation could be the last opportunity to gain a broad spectrum human rights protection and that the opportunity could not be lost.³⁶

Jeon and Haider-Merkell distinguish systems with multiple access points as being more receptive than others.³⁷ The New Zealand Parliament is a flat system of Government with limited access points. The authors also point to the role played by the media. First, the media can be used as a conduit to a wider constituency. Second, the media can shine the light of public attention upon an issue which has previously not had any attention at all. Third, the tone, which Baumgartner & Jones describe the way a policy issue is defined, or the development of its policy image, can determine the coverage the media will give an issue.³⁸

The tactics that DPA employed in the 1993 campaign present a puzzle. Having suffered a defeat in the 1990 legislative campaign DPA partnered with the AF to secure a broad definition disability clause, DPA took a risk when the possibility of securing a narrower

³⁵ Review of the Human Rights Commission Act 1977 Report to the Minister of Justice Human Rights Commission, August, 1987. Para.5.2

³⁶ Pers comm. Dave Henderson 21/3/12

³⁷ Jeon,Y &Haider-Merkell, D.P (2001) “Tracing issue definition and policy change: an analysis of disability issue images and policy responses” Policy Studies Journal Vol. 29 No.2 p.218

³⁸ See note 46

disability clause was present. This decision presents an even greater puzzle to solve when considering that DPA had so much to lose if they were not successful in 1993.

Tactics

When are lobbying activities most effective? Lowery argues that organisations set out not to influence in the grand sense but to survive.³⁹ If a group's core interests are threatened, even if the chances of success may be low, lobbying will be initiated.⁴⁰ Wright's example of the United States Congress' legislative threats to regulate against the tobacco industry is illustrative. Threats were met by tobacco industry lobbying even when the chances of success were low.⁴¹ This approach and subsequent response by interests or groups when they perceive core interests being threatened represents an almost last-gasp response. It differs greatly from the classical understanding of lobbying portrayed by the transactional model of a transaction of ideas and interests between parties.

The constituency that DPA represents, disabled people in New Zealand, were threatened when disability was not given legislative protection under the Bill of Rights. This makes the response by DPA, joining with the AF, when the Human Rights Act came before Parliament, a puzzling response. When the need for a legislative victory was so great, DPA chose to partner with a group that, while having shared interests, brought political risk as well.

Gleeson comments with relation to the ability of disability groups to participate in traditional transactional forms of lobbying that "the marginalisation of disabled people from mainstreams of power, including political spheres, has encouraged the practice of direct

³⁹ Lowery, D, (2007) "Why Do Organised Interests Lobby? A Multi-Goal, Multi-context theory of lobbying" *Polity* Vol.39, No.1 p.30

⁴⁰ *Ibid* at p.39

⁴¹ Wright, J (2004) "Campaign Contributions and Congressional Voting on Tobacco Policy 1980-2000" *Business and Politics* 6 p.1-26

action in public places”⁴² Gleeson points out with reference to Australia, that “the expectations of the state, in terms of behaviour and the role of disabled people leaves little room for political behaviour ... It is not simply that such groups are not part of political life ... but that such political action is not normally associated with disabled bodies.”⁴³

The point made by Gleeson with relation to disability groups and lobbying is that due to a marginalisation of the disability community from mainstream political activity other forms of activism have been employed, direct action and protest; the Rights not Charity March, UK 1988, the USA nationwide sit-in over the failure to implement regulations to section 504 of the Rehabilitation Act 1973, are prime examples.

Gleeson makes a further point specifically with relation to disability groups, as a result of the isolation that disability groups had after two decades of political activism, many were not used to dealing with Government directly; some were openly sceptical. Smith summarises the tension:

“they need to maintain a balancing act, needing to be close to government to be an effective change agent, whilst remaining separate.”⁴⁴

This contradiction is replicated within DPA who spent much of the time period from 1983-1990 protesting against the manner in which government treated people with disability, as well as DPA members participated in direct action during that time. From 1990 DPA made a switch to lobbying government. The comment by Smith is representative of one of the tensions that existed within DPA from 1990-1993. This tension is reflected by DPA’s Wendi

⁴² Gleeson, B (1999) *Geographies of Disabilities* Routledge, London

⁴³ *Ibid*

⁴⁴ Smith, K (2010) “Pushing the boundaries: the exclusion of disability rights groups from political influence in Victoria” *Australian Geographer*, Vol, 34, No,3, p.353.

Wicks, who illustrates the combative relationship with government, giving her opinion of the government strategy as it related to the disability community:

“Government, as a strategy, took path of least resistance ... ‘what would it take to get them off our back?’”⁴⁵

Issue Framing

Framing is one tool that advocates and policy entrepreneurs use to gain influence by shaping the way in which an issue is perceived by the general public and legislators. A frame, Gerrity notes, “can assign blame, define a problem, point to the cause, or imply a solution”⁴⁶ By providing elected officials with information about an issue advocates compete to frame the policy issue to decision makers.⁴⁷

Tierney argues that “political language works best when it is emotively appealing and logically compelling. It must win the hearts and minds of the electorate.”⁴⁸

What role do groups joining together around issues of importance have? What obstacles do groups face when attempting to join either internally or externally? Haider–Markel claims that by redefining an issue, groups may dismantle an existing “issue monopoly.”⁴⁹ Supportive of this concept and in conjunction with colleague Yongjoo Jeon, Haider-Markel conducted a study looking at the impact that definition usage had upon U.S. Congressional hearings that led to the passage of new disability legislation. Jeon & Haider Merkel concluded that “the

⁴⁵ Pers comm. Wendi Wicks 27/3/12

⁴⁶ Gerrity J.C. (2006) “Presenting a united front: similarities and differences between interest group and Congressional framing. Paper presented at the annual meeting of the American Political Science Association.

⁴⁷ Baumgartner, B.F & Jones, B.D. (1993) “Agendas and instability in American politics” Chicago, Ill, University Of Chicago, Press,

⁴⁸ Tierney M (2002) I am my rights: Public Relations Institute of Ireland, Dublin

⁴⁹ Haider-Merkell, D.P (1999) Creating Change – Holding the line : Agenda setting on lesbian and Gay issues at the national level In Riggle, E.B.D & Tadlock, B Gays and Lesbians in the democratic process: Public policy, public opinion, and political representation pp.242-268 Columbia University Press, New York, NY

results suggest that an increase in Congressional hearings usage of the social-political definition of disability significantly increased the likelihood that Congress will pass legislation based upon a socio-political definition of disability.”⁵⁰

Focussing specifically upon the disability movement, in a comprehensive study of the US disability movement Haider – Merkel found that several factors converged in the 1970s and 1980s to change how disability issues were viewed. First, a shift away from the medical concept of disability as a physical limitation coupled with the economic construct of disability as vocational incapacity and income problem. Second, the development of a new definition of disability along a social model of disability, which defines it as the result of an interaction by an individual with the environment. Third, the role the media plays in the debate, increasing the way in which the general public are made aware of disability issues, framing or defining the problems faced by disabled people. Fourth, disability groups were aided in attempts to redefine disability issues during Congressional hearings in which the socio-political view of disability dominated hearings.⁵¹

In order to understand the legislative framework in place when DPA lobbied to include disability provisions, it is necessary to first look at the origins of all disability legislation. The United Nations Year of the Disabled Person 1981 and resulting United Nations Standard Rules for the Equalisation of Opportunity for Disabled People (UNSR) were the origins of all disability human rights legislation. The next chapter charts the development of human rights legislation from the point of (UNSR) Rule 15, requiring all member states to pass legislation protecting

⁵⁰ *Ibid*

⁵¹ Haider-Merkell, D.P (1999) Creating Change – Holding the line : Agenda setting on lesbian and Gay issues at the national level In Riggle, E.B.D & Tadlock, B Gays and Lesbians in the democratic process: Public policy, public opinion, and political representation pp.242-268 Columbia University Press, New York, NY

the rights of disabled people. The chapter outlines the involvement of disability rights movements in the passage of disability discrimination legislation in the United States of America, Australia, and the United Kingdom.

Chapter 3 The United Nations and Disability

This chapter outlines the historical background to the enactment of legislation protecting disabled people from discrimination. It charts the genesis of disability discrimination laws from the International Year of Disabled Persons (IYDP) 1981 through to the United Nations Decade for Disabled Persons 1982-1993. All disability discrimination laws trace their origin to the Standard Rules on Equalisation of Opportunity passed in 1993 (UNSR),⁵² as the culmination to the UN Decade for Disabled People. Three national experiences deserve particular attention: The Americans with Disability Act 1990, the Disability Discrimination Act (Australia) 1992, and the Disability Discrimination Act (UK) 1995. The chapter outlines that, as a result of UNSR Rule 15, each member state passed anti-discrimination legislation. Of the countries focussed upon within this chapter, it will be argued that all accept Australia passed legislation with medical definitions of disability.

The United Nations and Disability

1981 International Year of Disabled Persons (IYDP)

In 1976, the United Nations proclaimed that 1981 would be the International Year of Disabled Persons. As part of the International Year for Disabled Persons (IYDP) the United Nations established a Plan of Action on Disability, later passed on the 3rd of December 1982 as the World Programme of Action on Disability. The focus of the Plan was to implement policy in three distinct policy areas; rehabilitation, prevention of disability and equalisation of opportunity. The Plan was to be implemented at Regional and International level. The focus for this thesis will be upon equalisation of opportunity, as that is the area that leads to the

⁵² Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993
<http://www.un.org/esa/socdev/enable/dissre00.htm> accessed 10/02/12

obligation upon member states to pass legislation that placed people with disabilities on a more equal status with non-disabled people.

The United Nations discovered as a result of the IYDP that a major barrier to the realisation of the goals of full participation and equality lay in the social attitudes of the general public.

The United Nations within The World Programme of Action contended that:

“Anyone in charge of any kind of enterprise should make it accessible to people with disabilities. This applies to public agencies at various levels, to non-governmental organizations, to firms and to private individuals”⁵³

Here the United Nations calls upon both governments and the private sector to provide equal opportunities for people with disabilities. Academic findings highlighted that there was significant work to do to achieve the goal as outlined by the United Nations as highlighted by members of the general public who had little exposure to people with disability.⁵⁴

The UN Decade of Disabled People ⁵⁵ established in 1983-1992 as being the timeframe in which “Governments should implement the recommendations outlined within the World Programme of Action on Disability”⁵⁶

The UN Decade of Disabled People

One of the major outcomes of the UN Decade was the adoption by the UN General Assembly of the United Nations Standard Rules on Equalisation of Opportunity (UNSR).⁵⁷ UNSR is not

⁵³ <http://www.un.org/disabilities/default.asp?id=23> accessed 25/7/12

⁵⁴ Gething L (1985) “Perceptions Of Disability Of Persons With Cerebral Palsy, Their Close Relatives And Able-bodied Persons”, Social Science & Medicine, pp.564

⁵⁵ General Assembly resolution 37/52

⁵⁶ <http://www.un.org/esa/socdev/enable/disunddp.htm> accessed 23 /3/12

⁵⁷ resolution 48/96 annex

legally binding upon member states but is a document that reflects the moral weight of the international community as passed by the General Assembly of the United Nations. UNSR outlines the preconditions for equal participation targets areas for state parties to promote equal participation, and provides a monitoring mechanism for signatories to report upon.⁵⁸ Legislation enacted to protect disabled people against discrimination is now a common feature in most countries. 153 member-states have ratified the most recent treaty on disability rights, the United Nations Convention on the Rights, of Persons with Disabilities.⁵⁹

United Nations Standard Rules (UNSR)

The driving purpose behind the enactment of the Standard Rules was a strong moral and political commitment by the governments of the world taking action to attain equality of opportunities for persons with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation. UNSR Rule 15 is of particular relevance to the enactment of anti-discrimination legislation. Rule 15 requires member state governments to enact either general or special legislation to meet this policy outcome.

National legislation concerning persons with disabilities may appear in two different forms. The rights and obligations may be incorporated in general legislation or contained in special legislation. Special legislation for persons with disabilities may be established in several ways: By enacting separate legislation to deal with disability matters exclusively, or by including disability provisions within legislation on particular topics; by mentioning people with

⁵⁸ <http://www.un.org/disabilities/documents/gadocs/standardrules.pdf>

⁵⁹ UNCRDP Is the most current Treaty to represent the rights of Disabled People, it originates from the UN Standard Rules on the Equalization of Opportunities for Disabled People adopted by the UN General Assembly forty-eighth session, resolution 48/96, annex, of 20 December 1993

disabilities in interpretation to legislation texts; or by a combination of the different approaches.

The New Zealand Government had a choice whether to enact a single piece of disability specific legislation or to include disability provisions from pre-existing Human Rights legislation. Part of the internal discussions that occurred within DPA, would focus upon whether to advocate for a disability-specific law or combine and gain broad human rights legislation. DPA chief Executive Dave Henderson sums up the thinking within DPA regarding whether DPA supported an ADA style piece of legislation:

“affirmative action from the US was a huge political football, and Parliament didn’t see any need for it”⁶⁰

Henderson’s previous point is highlighted by Anne Hawker DPA President during the passage of both the Bill of Rights Act 1990 and Human Rights Act 1993 that DPA wished to create rights-based legislation for all people who experienced discrimination and not carve out niche rights for disabled people exclusively.

“DPA made the decision not to advocate for ADA style legislation, for positive discrimination or affirmative action as DPA wanted an inclusive piece of legislation that included all people experiencing discrimination not a separate piece just for the disability community.”⁶¹

Here Hawker highlights a belief within DPA that all minorities within society experience discrimination and are deserving of protection. It is this belief and solidarity within DPA and

⁶⁰ Pers comm. Dave Henderson 21/3/12

⁶¹ Pers comm. Anne Hawker 28/3/12

within minority communities experiencing discrimination that drives the desire by DPA to lobby for an inclusive definition of disability.

The language of disability is important, it signifies to the disability community many things. It signifies the approach that the Government takes with regard to disabled people. Legislation adopting a medical definition signals to the disability that government policy would adopt certain views:

“Government talked the social model talk, but walked the medical model walk”, they walked the neo-liberal walk as well.”⁶²

The language of disability legislation

Certain phrases assume importance within disability discrimination legislation and are central to the interaction between the disabled community and the State. Key definitions, or terms, within disability legislation include: definitions of discrimination, and how employers ‘accommodate’ disabled employees. These terms are disputed between the disabled community and able-bodied community for the reason that the disabled community see disability in a very different light to the able-bodied community. This difference is expressed in the debate between Parsons and Oliver. Early theorists, such as Parsons, argued for a functionalist approach,⁶³ arguing that people with disability:

“... are exempt from the obligations and responsibilities that most members of society are expected to hold. Disabled people under this definition were undesirable, and for that reason were expected to seek professional assistance to bring relief to their situation.”⁶⁴

⁶² Pers comm. Wendi Wicks 27/3/12

⁶³ Parsons, T (1951) *The Social System* (Glencoe, The Free Press)

⁶⁴ Donoghue, C,(2003) “Challenging the Authority of the Medical Definition of Disability: an analysis of the resistance to the social constructionist paradigm” *Disability & Society* Vol.18 No. 2 p.200

This analysis grounds disability firmly within the individual. It was this model of disability that was used as the basis for drafting disability definitions until an alternative was put forward by members of the disability academic community in the 1970's challenging the dominance of the medical model. Led by disability activists such as Finkelstein, Oliver, Barnes and Barton, these activists challenged the assertion that disability is grounded within the person with the illness or with the disability. Oliver, who would go on to become a well-known academic, argued that external factors, such as societal stereotypes and personal prejudices act as barriers to access within society and these are the factors that keep disabled people from becoming fully integrated.⁶⁵

This broader debate about how disability is defined is important as it is central to the manner in which the state defines disability within discrimination legislation. The question of definition within a piece of legislation also goes as evidence as to which stance the State takes in the policy creation process over the issue of disability. When the state adopts a medical definition of disability it is in effect taking a view upon disability and anti-discrimination based upon the medical definition of disability.

By adopting a definition which explicitly states that disability is grounded within the individual, the state is taking a position which states that the discrimination disabled people encounter is directly connected to their impairment. The state does not seek to include or examine whether wider societal factors are involved.

A state that takes a wider definition or view of disability equally takes a view that disability represents a broader relationship than just the personal impairment or condition of the

⁶⁵ Oliver, M A (1988) Sociology of disability, or disabilist sociology? in Barton, L (Ed) Disability and Society p 18-42 (London and New York, Longman)

disabled person. The state takes a view that a person can be 'disabled' by the environment around them, including such things as inaccessible environments, discriminatory attitudes and social stigmas.

The (UNSR) Rule 15 is the instrument that requires member states to pass legislation protecting the rights of people with disabilities.

The UN distinguishes between physical limitation or impairment and any resulting loss of opportunity due to the impairment. By making this distinction the UN states that there is a separation between the physical limitation and any negative social outcomes that result from the physical limitation.

UNSR defines disability as:

“any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a ‘human being’

Whereas UNSR defines handicap as:

“a disadvantage for a given individual, resulting from an impairment or disability, that, limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual”

This thesis now looks at discrimination legislation within the United States, Australia and the United Kingdom, at how each defines disability, what meaning each gives to discrimination, the accommodations given to employers and the role the disability community played in the passage of each law.

Definitions of Disability

Americans with Disability Act (ADA) 1990

The Americans with Disability Act (ADA) 1990 defines disability narrowly, limiting it to categories of impairment such as physical and mental impairment. The definition requires that the impairment substantially affects one or more major life activities and that there be a record of the impairment. In addition the impairment must be non-transitory, such that it must last for more than six months.

One comparative omission from the initial ADA definition of disability was 'presence of organisms in the body capable of causing disease'. In subsequent Federal Court decisions, the definition has been broadened. The following impairments have been deemed to fit under the disability definition of ADA: HIV infection,⁶⁶ nerve damage causing the inability to walk,⁶⁷ sterility / infertility,⁶⁸ and mental illness / insanity.⁶⁹ Due to Federal Court interpretation of the disability definition, the reasonable accommodation provision and the undue hardship

⁶⁶ Bragdon v. Abbott, 524 U.S. 624 (1988).

⁶⁷ EEOC v. Sears Roebuck & Co., (7th Cir. 2005)

⁶⁸ Yindee v. CCH Inc. , 2006 U.S. App. LEXIS 20576 (7th Cir. 2006);

⁶⁹ Josephs v. Pac. Bell, 443 F.3d 1050 (9th Cir. 2006)

provisions of ADA have resulted in the Congress introducing the ADA Amendment Act 2008 to restate the original intention of Congress.

Disability Discrimination Act (Aust) 1992

The definition of disability under ADA is significantly narrower than the Australian definition under DDA (Aust) 1992, which broadens out the definition of disability to include:

“loss of bodily function, either total or partial presence of organisms in the body capable of causing disease, malfunction, malfunction, disfigurement of a person’s body, disorders, resulting in learning differently or disorders resulting affecting thought process. The definition also extends to disabilities that presently exist, have previously existed and may exist in the future and to persons to whom a disability may be imputed”⁷⁰

During its passage through both houses of parliament DDA (Aust) 1992 received both support and criticism from both sides of the House. Support for the Bill came from the Minister for

⁷⁰Disability Discrimination Act 1992 - SECT 4

http://www.austlii.edu.au/au/legis/cth/consol_act/dda1992264/s4.html Accessed 20/4/12

disability” , in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental [functions](#); or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction;

or

(g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a [disability](#) that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future (including because of a genetic predisposition to that [disability](#)); or
- (k) is imputed to a person.

To avoid doubt, a [disability](#) that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the [disability](#).

Health, Housing and Community Services, Hon. Brian Howe, who described the Bill in these terms:⁷¹

“... the bill was an overdue and significant step in fulfilling Australia’s International obligations”⁷²

Howe ⁷³ emphasised the importance of the Australian Government’s commitment to social justice and reform, which in the Minister’s mind was evidenced by sex and racial discrimination legislation and the Disability Services Act 1986. Detractors of the Disability Discrimination Act 1992 (Aust) argued that the definition of disability was too broad,⁷⁴ and the inclusion of HIV/Aids also was criticised. Senator Meg Lees⁷⁵ was critical of the Bill argued that it did not go far enough to advance the rights of disabled people, but was “better than nothing.” ⁷⁶ The definition contained within the DDA (Aust) is wider than the definition included in statutes passed in the United States, United Kingdom and New Zealand.

⁷¹Disability Discrimination Bill 1992 Second Reading (House Hansard, 26-05-1992 chamber /mansard/1992-05-26/0039

⁷² Australia1992a p.2751)

⁷³ Brian Howe was Minister for Health, Housing and Community Services in the Government of Prime Minister Bob Hawke. Howe was appointed Minister in 1990, dropping the portfolio in 1993.

⁷⁴

- (a) total or partial loss of the person's bodily or mental [functions](#); or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction;

or

- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour

and includes a [disability](#) that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future (including because of a genetic predisposition to that [disability](#)); or
- (k) is imputed to a person.

To avoid doubt, a [disability](#) that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the [disability](#).

⁷⁵ Senator Meg Lees, was the State Senator for South Australia for the Democrats from 1990 to 2002 and as an independent with an association to the Australian Progressive Alliance from 2002 till her retirement in 2005., Senator Lees held portfolios and responsibilities in the areas of Community affairs, Community and family, Aged Care, Women and the Status of Women and Social Security.

⁷⁶ Australia, 1992c p.1316

Disability Discrimination Act (UK) 1995

The Disability Discrimination Act (UK) 1995 takes a narrow definition of disability, defining disability as follows:

“a physical or mental impairment which has a substantial or long term adverse affect on [the persons] ability to carry out ‘normal’ day to day activities”⁷⁷

This definition focuses upon physical limitation and whether a person is capable of carrying out ‘normal’ activities. The use of ‘normal’ within a statutory definition is subjective at best. The definition concludes with a requirement that the impairment have an impact upon the person’s ability to carry out ‘normal’ day to day activities.

‘Normal’ day to day activities are defined within the Act as follows:

“mobility, manual dexterity, physical coordination, continence, the ability to lift and carry or move everyday objects”⁷⁸

By setting the definition of disability narrowly the DDA (UK) excludes several groups from protection. First, people with long term impairments not ‘deemed’ serious enough as no serious adverse effects are evident. Second, people with short term impairments are completely excluded, no matter how serious the impairment. Third, those with progressive conditions (such as Multiple Sclerosis and HIV) which are yet to manifest an effect, serious or not, upon their functional ability, and Fourth, those for whom disability is attributed, such as

⁷⁷ UK DDA s.1 (1)

⁷⁸ UK DDA Schedule 1 para 4

the carers or partners of people with disabilities or the working colleagues of people with disabilities.

In addition a person who has a physical impairment or a mental impairment or mental illness will only meet the threshold of impairment under the DDA (UK) when it is “clinically well recognised.”⁷⁹ This is controversial due to some disabilities not being clinically well understood, such as autism and schizophrenia.

‘Long term’, is defined as having lasted or is likely to last for at least 12 months, or is likely to last for the rest of the life of the person affected. Persons with short term disabilities (less than 12 month’s duration) are not protected.

Disability rights movements would play differing roles in the passage of discrimination legislation in United States, Australia and Great Britain. Does an actively involved disability movement necessarily lead to legislation that benefits disabled people or can Parliaments pass legislation without the involvement of an active movement? These are questions that require examination of the role that the disability movements in the United States, Australia and Great Britain impacted the passing of disability legislation in each country.

The disability rights movements’ impact upon the legislative process

The US disability rights movement role in the passage of the ADA

The disability movement in the United States of America traces its history back to the 1960s. The movement began with foundation members within University settings, Ed Roberts in Berkley, California and Judy Heumann in New York. Heumann sums up the attitude of disability activists within the United States:

⁷⁹ UK DDA Schedule 1 para 1

"... as long as you believe that your life is a tragedy, you can't do very many good things with your life. Once you believe that the tragedy isn't your fault, that it is the failure of the political system to acknowledge your rights as a human being, to be equal in society that you can as an individual have a voice as part of a group, and then you can make a difference."

Here Heumann clearly identifies the political system as being at fault for not acknowledging the rights of the disability community. In identifying the system as being at fault and needing to change Heumann adopted civil rights era language. Activists were able to utilise tactics garnered from civil rights era campaigns during their own grass roots campaigns,⁸⁰ as well as borrowing the language from other struggles such as the racial, religious, and gender discrimination, allowed disability campaigners to incorporate the struggles of previous eras into their own campaigns.⁸¹

In the period 1981 to 1990 conservatism in America was reflected in the White House by the Reagan and George H.W Bush Administrations. The disability lobby partnered with conservative 'right to life' groups over the issue of government protection of new-born disabled children from physician-led decisions to withhold treatment. Paige and Karnofsky, describe this pairing as 'difficult to put together and difficult to sustain'.⁸² The disability lobby would need to pair with more unusual partners in the future to achieve legislative success. The disability rights movement partnered with the gay rights movement. What may seem an unusual pairing at first is quickly dispelled by gay people who are disabled. The disability rights

⁸⁰ Scotch, R.K (1989) "Politics and Policy in the History of the Disability Rights Movement" *Milbank Quarterly*, Vol. 67, Supplement 2 (Part 2). *Disability Policy: Restoring Socioeconomic Independence* . pp. 380-400, 388

⁸¹ Scotch, R.K. *From Good Will to Civil Rights: Transforming Federal Disability Policy*. Philadelphia: Temple University Press (1984)

⁸² Paige, C and Karnofsky, E.B (1986) "The Anti Abortion Movement and Baby Jane Doe" *J Health Politics and Law* 11, 255-269

movement's involvement in the passing of ADA proved to be crucial. The movement began a ground up campaign that spread across the whole nation, resulting in a groundswell of public opinion converging upon Washington along with the stories of the activists.

What made the passage of the bill inevitable was the combination of three factors.

First, political support from both sides of the House and in both Houses. The ADA was popular in both the House and Senate due to a sustained lobbying effort by both the disability lobby in Washington and by members of Congress with a personal interest in disability or at least a sympathy and empathy for the issue.

Second, Presidential support: President George H.W. Bush had stated he was supportive of the Bill becoming law.⁸³

Third, grass roots campaigns by disability activists to gain support for the bill. During this process stories of discrimination were gathered from across the United States and when the Bill came before the Senate committee heartfelt testimony from the disability community was impossible to deny by committee members.

The combination of the power of the stories of the activists, and the power of their narrative, combined with a real determination within Washington, both at bureaucratic and interest group level that the ADA was an important piece of legislation whose time had come. The combination of all these factors; a united Congress; a President who publically stated his preference for the Bill to be passed; and the result of grass roots campaigns of disabled activists culminating in activists and ordinary citizens with disability giving testimony to Senate hearings on the Bill made its passage almost inevitable.⁸⁴

⁸³Shapiro, J.P. *No Pity: People With Disabilities Forging A New Civil Rights Movement* (Random House, 1993 / Three Rivers Press, 1994,

⁸⁴ See note 70

The Australian disability rights movement role in the passage of the DDA (Aust)

During the passage of the DDA (Aust) 1992, the Australian disability rights movement had little or no input during drafting or when the Bill went through Federal Parliament. The disability rights community has been described as 'fragmented and arranged at national level around disease types'.⁸⁵ Disability rights movements complained that the DDA was marked with inequities, especially placing the onus upon individuals to take complaints against well-resourced organisations in the private sector.⁸⁶

The Australian Federal Parliament commissioned reports examining the need for anti-disability discrimination legislation. Of those surveyed 95 % favoured national disability discrimination legislation covering employment, education, transport and public mobility in opposition to a previously proposed limited employment discrimination legislative option.

Australia had no single umbrella disability organisation, representing in a unified way the views of the disability community. Newell suggests this reflects the fact that in Australia there is a dominance of charitable organisations for disabled people "and a lack of well- educated and articulate disability advocates ..."⁸⁷

The Australian disability rights movement played a minimal part in the passing of the DDA 1992 (Aust). Newell comments that there was not the up-swell of educated and skilled disability activists in the Australian situation.⁸⁸

The disability movement in Australia faced significant challenges in simply mobilising advocacy groups due to the vast size of the country. The task of getting groups in the same

⁸⁵ Newell, C (1996) "The disability rights movement in Australia: a note from the trenches" *Disability & Society* Vol.11 No.3 p.429-432 at 430

⁸⁶ Newell, C (1995) "Consumer reflections on the Disability Discrimination Act" *Australian Disability Review*, no.2, 1995: 60-65

⁸⁷ *Ibid* at 429-432

⁸⁸ ⁸⁸ Newell, C (1995) "Consumer reflections on the Disability Discrimination Act" *Australian Disability Review*, no.2, 1995: 60-65

place at the same time has proven financially prohibitive. This in turn had led to reliance upon State / Commonwealth funding, which lead to concerns of a lack of independence.⁸⁹ Australian disability rights groups have not utilised direct action to the extent that their US and UK counterparts have in campaigns for legislative change. Newell suggests this is due to a lack of power and unity, a valid concern expressed by Newell given the geographical and organisational impediments to the movement's active participation. In addition, the lack of direct action could stem from a 'capture effect', with the movement not wanting to jeopardise the possibility of future funding.⁹⁰

The British Disability rights movement's role in the passage of the DDA (UK) 1995

The disability movement began to emerge as a political force in the 1960's when two groups came together to protect the interests of disabled people in residential institutional institutions. First, the Disablement Income Group (DIG) established in 1965. Since its creation it lobbied Parliament for better disability benefits, and has attempted to focus attention upon poverty within the disability community, second, as a result of failures to secure comprehensive disability income, the Disability Alliance (DA) was formed as an umbrella organisation, in 1975.⁹¹

The Union of the Physically Impaired Against Segregation (UPIAS), created in 1975, developed the principles which went onto be used to argue for the creation of disabled people's

⁸⁹ Cooper, M (1999) "The Australian Disability rights movement Lives" (1999) *Disability and Society* Disability & Society, Vol. 14 No. 2 p.217-226

⁹⁰ Newell, C (1996) "The disability rights movement in Australia: a note from the trenches" *Disability & Society* Vol.11 No.3 p.429-432

⁹¹ Barnes, C & Oliver, M (1995) "Disability rights: rhetoric and reality in the UK" *Disability & Society*, Vol 10 No 1,

organisations worldwide and to form the basis for the social model of disability. UPIAS strongly argued that:

'We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us' (UPIAS, 1976, pp. 4-5).⁹²

UPIAS was central in the creation of the social model of disability which rejected the medical model of disability as outlined in the impairment definition: 'any loss or abnormality of psychological, physiological, or anatomical structure or function'⁹³ but included disabling environments:

'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities'⁹⁴

The efforts of the disability rights movement in the United Kingdom were crucial on two levels in placing the need to have disability discrimination legislation on the agenda of the conservative government.

Research conducted in 1992, by British disability academic Colin Barnes demonstrated for the first time that disabled people were being actively discriminated against. Prior to that date

⁹² 'Doing Disability Research (1997) Colin Barnes and Geoff Mercer (Eds).Leeds, The Disability Press, pp. 1-14).

⁹³ *Ibid*

⁹⁴ *Ibid*

the government in Britain did not accept that disabled people were actively discriminated against within society.⁹⁵ Second, the international disability rights movement played a part in mobilising the disability community as a movement, the British movement adopted strategies from their US counterparts within the civil rights and ILM (Independent Living Movement).⁹⁶ Disabled people in Britain were now prepared to risk public ridicule, arrest, and imprisonment.⁹⁷

The British disability movement voiced publically a belief in human rights, founded upon a determination that disabled people had rights and those rights needed legislative expression. A key focal point for disability activists was the July 1988 'Rights not Charity' march.⁹⁸ This demonstration was a direct response to the passage of the Social Security Act in April 1988. The disability community in Britain believed passage of the Act would force disabled people, especially disabled people previously in institutional care back into institutional care which was a major fear of the Independent Living Movement (ILM). Participants in the march proceeded on wheels and foot to the offices of Nicholas Scott, Minister for Social Security and Disabled People to present a letter of protest. Upon arrival, Scott refused to meet the protesters or to receive the letter. At this point the protesters parked up or sat down at a roundabout on a busy intersection in the vicinity of the Ministry, blocking traffic.⁹⁹ This

⁹⁵ Barnes, C (1991) Disabled people in Britain and discrimination: A case for anti-discrimination legislation,

⁹⁶ Barnes, C, Disability and Employment" (1992), University of Leeds, (British Council of Organisations of Disabled People)

⁹⁷ Barnes, C Disabled People in Britain and Discrimination (London, Hurst & Co), Hasler, F. 1991 'The International Year of Disabled People', *Disability Now* January, p. 5, Oliver, M. 1990 The Politics of Disablement London: Macmillan

⁹⁸ This march is important on two levels, first, it signals the UK DRM taking action from a spillover effect of its US counterpart, direct action, to gain legislative change. Second, it signals the change from a Charity based understanding within the disability sector to one of rights. The Disability sector witnessed a monumental power struggle between people with disabilities wanting to control their own destinies and those, non-disabled people, historically who, with often with good intentions, controlled disability organisations.

⁹⁹ Wilkinson, M Defying Disability: The Lives and Legacies of Nine Disabled Leaders (2009) Jessica Kingsley Publishers. P.70-71

protest signalled a watershed within the British disability movement. First, it indicated that disabled people within Britain were prepared to engage in civil disobedience over a rights issue and second, as a result of the march the phrase “rights not charity” was adopted by disability movements worldwide. It is now part of the common vernacular, signifying a process of transition that disabled people make from being viewed as charitable burdens upon society to viewing themselves as citizens who rightfully enforcing their civil, political, and social rights.

The growing strength of both the UK and US disability movement, demonstrated through the ‘Rights Not Charity’ march in the Britain and the United States movement mobilising to such a point that it was the driving force behind the passage of the ADA 1990, indicates that something was happening within the disability community worldwide. Disability people were transitioning from a minority of people that had traditionally been subject to oppressive conditions socially, economically, politically, and were starting to educate themselves and to become politically active. This growth in strength and political engagement is contrasted with the experience of the Australian disability rights community who were effectively shut out of the process of passing the DDA Act 1992. Consultation between the Federal Government and disabled people was handled within a pre arranged Federal consultation disability board and no external involvement with the disability community was sought.

The study of disability organisations as political organisations has not been a focus of academic attention within New Zealand. Authors such as Sullivan¹⁰⁰ and Munford¹⁰¹ have explored disability and disability organisations deeply as a sociological phenomenon. Sullivan

¹⁰⁰ Sullivan, M (2001) Disabled people and the politics of partnership in Aotearoa New Zealand. In L. Barton (Ed.) (Eds.). Disability, politics and the struggle for change

¹⁰¹ Munford, R (1994) Caregiving - ‘a shared commitment’ in Ballard K (Ed) Disability, Family, Whanau and Society,

has published at least 38 journal articles, book chapters, conference presentations, oral presentations and reports in the area of disability. Sullivan uses resistance and emancipatory approaches to analyse the impact institutions within in the health and disability sector have upon disabled people's ability to exercise their rights. The focus for Sullivan is disablism and disabling structures rather than the collective organisations that represent people with disabilities as political entities. Authors such as Humpage look at the social citizenship rights of disabled people in New Zealand and the impact of neoliberal reform upon public opinion of disabled people's citizenship rights. Humpage does not focus on the role of disabled people's organisations when achieving legislative ends aiding the citizenship rights of disabled people. A gap exists within the research in terms of understanding the role of disabled people's organisations as political entities achieving political goals. The purpose of this research is to begin to fill that gap by looking at the disabled person's organisation DPA taking part in the political activity of lobby during the period 1989-1993.

The purpose of choosing the two instances of lobbying by DPA is twofold; first, the lobbying to include disability into the Bill of Rights in 1990 and again, the lobbying to include disability as a prohibited ground of discrimination within the Human Rights Act demonstrated that disabled people's organisations could achieve political aims and second, by outlining these instances of lobbying, highlighting the differences in techniques between the 1990 and 1993 campaigns, conclusions can be drawn for future lobbying by disabled people's organisations.

The next chapter will outline the genesis and growth of the disability movement in New Zealand. Particular attention will be paid to (DPA) NZ from its inception in 1983 through to 1990.

Major themes within the chapter will be the influence of the 1981 (IYDP), how it impacted upon the newly created DPA and upon disabled people themselves. It will be argued that IYDP was a key driver that led to a shift in both government policy as well as a rise in consciousness the disability sector that led to shift away from a charity ethic and a movement toward a human rights focus.

Chapter 4 Disability advocacy in New Zealand from 1981 - 1990

Disabled people have long lived in the shadows in New Zealand, behind the doors of institutions, or behind the protective walls of their families. The IYDP sent a message both to disabled people and to the able-bodied community in New Zealand and throughout the world that it was now time for disabled people 'to come out of the shadows'.

This chapter will argue that within New Zealand the disability community participated in a rise in both personal and political consciousness as a result of the IYDP. This led to a 'changing of the guard' within organisations that had previously represented disabled people but been staffed and ran by non-disabled people.

The IYDP changed the way disabled people saw themselves. This process began by bringing disabled people out of the shadows and into the living rooms of ordinary New Zealanders through a high profile telethon event. This was held in 1981, the same year as the IYDP. For many able-bodied New Zealanders it was the first opportunity to see a disabled person. These events led to a shift within the disability community whereby disabled people no longer wished to be represented by non-disabled people on issues relating to disability. This process is best described as:

“... a militant, revelational process aptly described as ‘nothing about us without us’”.¹⁰²

¹⁰² Charlton, J.L (2000) *Nothing About Us Without Us: Disability Oppression and Empowerment*, University of California Press, Berkley, p.4
“Nothing about us without us” has since been adopted as the international catch cry of the global disability movement

The process can also be described as the disability community was moving from being a group who had historically been in receipt of charity from both the state and general society to a group claiming human rights for disabled people in the form of legislative protection. If there is one disability organisation within New Zealand that embodies that shift it is DPA NZ. Its creation will be outlined below. By the end of the decade disability organisations were evolving to be controlled by disabled people themselves. Disabled people's organisations had legitimate fears of working with non-disabled organisations, fears that to do so would 'water-down' hard-won control over disability issues.

The chapter will conclude with DPA on the brink of beginning the lobbying to include disability within the Bill of Rights 1990 as an organisation fired up from the period 1980-1990 and imbued with a sense that disabled people in New Zealand were in desperate need of legislative protection.

International Year of Disabled People (IYDP) and its linkage to the disability movement in New Zealand

1981 was declared by the United Nations to be the International Year of Disabled People (IYDP). IYDP is linked to the creation of the disability movement in New Zealand as the result of ruptures in the cohesion of the international disability movement. In preparation for IYDP a 'charter for the 80s' was prepared by Rehabilitation International (RI), an international nongovernmental body founded in 1922. RI currently represents a worldwide network of people with disabilities, service providers, government agencies, academics, researchers and advocates.¹⁰³ In 1980 at the time of the 14th Congress in Winnipeg the RI Board had a majority of non-disabled doctors and physiotherapists and other specialists in the area of rehabilitation. Perhaps the bigger story to come out of the Winnipeg Conference, (when the Charter of the 80s' was being launched and IYDP was being tested in front of disability groups themselves), was the mass walk out by a group which was majority controlled by disabled people from the Conference, after Disabled People International (DPI), a group representing the rights and interests 'of' disabled people, was prevented from speaking at the Conference.¹⁰⁴

The reason why the walk out was important and symbolic to the disability community was at the time of the Conference, Rehabilitation International (RI) represented service providers to the disability community. RI was an organisation made up from mainly non-disabled doctors and physiotherapists. There was very little disabled representation within the RI board. The significance of the DPI walk out was seen in the structure of Disabled Person International

¹⁰³Rehabilitation International is an INGO founded in 1922. RI works to promote the interests of disabled people at an international level and monitor implementation of CPRD by state parties. <http://www.riglobal.org/> accessed 13 / 3 / 12

¹⁰⁴ Pers Comm. Wendi Wicks 21 / 5/ 12

(DPI), a group made up of a majority of people with disability. When DPI was not granted speaking rights at the Winnipeg conference it sent a message to the disability community that they could be present but their 'voice' was not wanted.

The New Zealand representative, Mr Bill Maddren, who had been Secretary of the Auckland Coordinating Council for Disabled Persons (ACCDP),¹⁰⁵ attended the meetings with disability groups when the decision was made to walk away. In Wicks recollection, Maddren came away from the Winnipeg conference of the opinion that the New Zealand Council was on the right track to cope with likely future developments, both as an organisation but also for people with disabilities.¹⁰⁶ Here Wicks comments on the decision by DPI, supported by Maddren of ACCDP to walk away from the Winnipeg Conference in support for DPI being refused speaking rights. What Wicks is speaking to is a determination not to let non-disabled people speak for disabled people, as had long been the case.

This symbolic action represented the first flickers of a sea change of consciousness within the disability community. It was one that would eventually lead the community to demand protection against the worst kinds of discrimination experienced in areas such as employment, access to transport, accommodation, recreation, and education.

The relevance of the IYDP to Disabled People

Prior to 1981, the disability community was represented by large charities who engaged in advocacy on the behalf of the disability community. In New Zealand, these charities included the IHC and the New Zealand Foundation for the Blind. Able-bodied representatives of

¹⁰⁵ACCDP would go on to be part of the group that formed DPA NZ, Bill Maddren would take part in the negotiations to create DPA.

¹⁰⁶ Pers comm. Wendi Wicks 21 / 5 / 12

disabled people controlled these organisations: the New Zealand disability movement was largely led by “able-bodied parents of children with disabilities”.¹⁰⁷

A similar situation existed within Britain, where disability representation was largely the same; Scope, Leonard Cheshire and Mencap were long standing charities with able-bodied members representing the views of the disability community. Hunt puts forward a personal view as regards the way by which volunteers and staff adopt a “do gooder” mentality which often disadvantages people within their own organisations.¹⁰⁸

The impact upon disabled person’s organisations of the IYDP cannot be over stated. Prior to 1981 disabled people were by and large represented by well-meaning people who had no lived experience of disability and could not advocate with that experience in mind on issues of disability. The IYDP was fundamental in encouraging disabled persons organisations to form by requiring Governments to foster their formation. IYDP also provided seed funding for projects that have had long lasting impact.

The IYDP, as Lucas, points out has several important aspects. First, it acted as a focal point for the disability community to recognise that their plight was being given attention by not only their own governments but at an International level as well.

¹⁰⁷“Equality through Participation” Interview with Anne Hawker NZJDS 3 (1996)

¹⁰⁸The April report: report / of the Royal Commission on Social Policy. Royal Commission on Social Policy People with Disabilities, pg . 786-803

Second, the year allowed the disability community to 'come out from the shadows' where previously disabled people had not been seen participating in public activities, IYDP gave the impetus for disabled people to venture out into the world.

Third, IYDP allowed for groups of disabled people to join together and to support each other. IYDP sent a message to the disability community that groups 'of' disabled people could and should exist and could represent the rights of disabled people just as well, if not more effectively than able-bodied groups.¹⁰⁹

This point was emphasised by Ann Ballin, the New Zealand IYDP National Chairwoman, who argued that the New Zealand disability community also needed to take a hard look at its understanding and knowledge of disabilities other than their own.¹¹⁰

Tensions within the disability community as the result of IYDP

The IYDP gave the disability community legitimacy by putting the issue of disability on the political map. While IYDP brought the stories, and lives of the disabled communities to the attention of the able-bodied community a tension emerged in the committees that ran IYDP on a local basis.

Within the New Zealand disability community a definite state of tension existed over the IYDP. Two main issues resurfaced. First, the manner in which IYDP was being administered reinforced old stereotypes for the community about decisions being taken on their behalf and

¹⁰⁹ Lucas, E "1981 International Year of Disabled Persons" AOTJ 1981 28(3) 95-99

¹¹⁰ Ballin, A (1982) "Where have we got to go after 1981? A Review of the International Year of Disabled Persons" Access, (CCS Disability Action Library)

in their best interests. IYDP committees were set up regionally. Each had a disabled representative when established, but the committees were not, in the words of Hawker, 'of disabled people'. What Hawker means here is, reflecting the views of the disability community'.

Some within the disability movement at the time felt that disabled representatives on the committees were a sign of 'tokenism'. Hawker illustrates the process by which disabled people were being used to front IYDP committees:

“... a few high profile disabled people being used as front people, in Dunedin, Barry de Geest was the front person of the IYDP committee,” ¹¹¹

There was conflict between the members of the committees and disabled members who believed they were being used as tokens had something meaningful to contribute and able-bodied members who thought they knew it all because of some past involvement with the disability community.” ¹¹²

The lesson taken from the 'walk out in Winnipeg' was that the disability movement needed to be responsible for matters that related to disabled people. This would mean controlling the decisions that affected the disability community and having a significant input upon Government policy relating to disabled people. Both Hawker and Hunt agree that during IYDP there existed significant tension between the disability community and the government relating to the way the community was being consulted over IYDP. Both are of the opinion that disabled people were being used as tokens to achieve political aims and real control over disability issues was, at this point, not within the grasp of the community.

¹¹¹ Pers comm. Anne Hawker 28 / 3 / 12

¹¹² "Equality through Participation" Interview with Anne Hawker NZIDS 3 (1996)

Second, as emphasised by Hunt, the ‘charity ethic’, by which policy makers and providers of services assumed responsibility for the decisions taken and methods used in the care of disabled people, without any consultation with disabled people themselves, resulted in disabled people being placed in a model of ‘patient’ to be ‘pitied’ while surrogating the needs of the disabled person to the system by which the services are being delivered.¹¹³

Hunt argues that at this time members of the disability community were benefiting from tertiary education. The disability rights movement was changing and the community was swelling with knowledgeable, empowered, activists.¹¹⁴ Hunt argues that the rise in knowledge, skills and a focus of activists upon human rights is partly responsible for the shift from a charity model to a human rights model.

Curry agrees, commenting on the rise in activism during the period, supporting the message that the disability community could be heard, as a community that had not previously been heard, Curry also notes the broader point that the period witnessed the decline of the charity model and the rise of the social / citizenship model of disability.¹¹⁵

The impact of the IYDP on Disabled Persons Organisations

The first major event that had an impact upon the disabled people’s movement was the 1981 Television New Zealand telethon. The telethon event raised in excess of 6 million dollars for the disability community and at the same time the event brought back into the memories of disabled people issues just exactly how disabled people were portrayed to the general public

¹¹³ Refer note 8

¹¹⁴Pers Comm. Robyn Hunt 29 / 3/ 12

¹¹⁵Pers Comm. Paul Curry 15 / 2/ 12

at that time and how disabled people's organisations relate to the wider community and how resources are used.

1981 Telethon

The 1981 Television New Zealand telethon was dedicated to raising money for disabled children, the event raised more than \$6 million. The funds would eventually be used to establish 'Total Mobility', Teletext and many other projects. For a large section of the New Zealand able-bodied community telethon was the first experience seeing a person with a disability.

During the telethon, disabled people worked as volunteers behind the scenes, 6500 worked on the production of the event, particularly children as well who also worked as performers. Disabled people volunteered in such roles as telephonists, cleaners; sat on celebrity panels, answered phones taking pledges, and disabled entertainers took a tongue and cheek look at the 'normal' minority.¹¹⁶ As a result of telethon, Television New Zealand made 65 programmes on or about disabilities which greatly increased the exposure of people with disabilities to the general population.¹¹⁷

Expressing one side of the tension felt within the disability movement, Hunt believes that the manner in which disabled people were portrayed during telethon was "exploitative and resulted in negative images of disabled people continuing to be associated with charity." Hunt also contends that "any benefit that came to the disability community in the form of the more than \$6m was undermined through use of disabled people as pity objects."¹¹⁸ This view is

¹¹⁶ AiD, July, 1981

¹¹⁷ AiD, July, 1981 p.3

¹¹⁸ Pers Comm. Robyn Hunt 29 / 3/ 12

supported by Wendi Wicks, who describes the “immediate gain, which resulted from telethon did not address the portrayal of the stereotypes of disabled people and the portrayal of disabled people of objects of pity.”¹¹⁹ Wicks describes how disabled people are still ‘the other’ are still portrayed as ‘receiving’ despite the fact that the other may be a little bit better off.¹²⁰

Expressing the other side of the tension felt within the disability community is past DPA president Dave Henderson, who has a slightly differing perspective upon the portrayal of people with disability during telethon. Henderson reflects that the portrayal was “reflective of the dominant culture of how disability was portrayed at the time. A portrayal [which in the opinion of Henderson], is not present now”.¹²¹ Henderson suggests that there were negative portrayals of people with disability at that time but that was not isolated to telethon, but more reflective of the cultural norms of the time, in Henderson view, “telethon was not a ‘standout’”.¹²² Henderson points out that “activists such as Robyn Hunt had a huge role in changing the language society used to describe disability”.¹²³

Telethon: Where did the money go?

The funds raised have had a long-lasting impact, being used to set up such well known services as Teletext, and other not so well known services as Total Mobility and the National Library ‘talking book’ service. Teletext, the information based system that is now common place but in 1981 was very new, allowed speechless communicators a method to interact with the medium of television. A total of \$750,000 was set aside for the project.

¹¹⁹ Pers Comm. Wendi Wicks 27 / 3 / 12

¹²⁰*ibid*

¹²¹ Pers comm. Dave Henderson 21 / 3 / 12

¹²²Pers comm. Dave Henderson 21 / 3 / 12

¹²³*ibid*

The Total Mobility scheme encourages, through subsidy, taxi companies to purchase modified taxi vans that are able to safely and securely transport passengers with wheelchairs to their destinations. Grants from the IYDP totalling \$200,000 were extended to the scheme after initial requests for \$2,000,000 were requested. Total mobility was a scheme whereby disabled people in rural areas receive subsidised taxi usage for a door to door service.

Telethon allocated \$100,000 to the project to put books on tape; this project is especially beneficial to blind persons and especially to blind children learning to read.

The project was supported by the National Library 'talking books' service who estimated that, "in addition to the 3000 talking books in use by the Royal Foundation for the Blind, many more talking books would be used by blind people if available from local libraries."¹²⁴

In a commentary on whether the ends of securing the \$6m of funds for the disability community, justify the means utilised to secure those ends, Wicks comments:

"In my judgement, the ends did not justify the means, however there are a lot of people who see the money and whose need is great and are convinced by expediency, people are convinced by the possibility of having life a little bit easier / normalised."¹²⁵

Wicks comments that "If life is a struggle and someone offers them [disabled people] a way to make it just that bit easier then the ends do justify the means."¹²⁶

Hunt describes the 1981 telethon as "disgraceful, relying on the worst stereotypical conceptions of disability, doing nothing to empower the disabled participants who took part,

¹²⁴ IYDP Trust, 1984 (CCS Disability Action Library)

¹²⁵ Pers Comm. Wendi Wicks 27 / 3 / 12

¹²⁶ Pers Comm. Wendi Wicks 27 / 3 / 12

there was no participation of disabled people in the organisation of the event; it was the worst example of the charity model.”¹²⁷ Hunt’s points out that “that any benefit that came to the disability community in the form of the \$6m was undermined through use of disabled people as pity objects.”¹²⁸

Telethon provides an interesting point of focus to distinguish a charity approach from a human rights approach. The telethon event was intended to benefit the disability community by raising money to fund the community but in the process of raising money the community was, in the opinion of both Hunt and Wicks exploited. Relying upon charity and pity for donations are, in the opinions of both Hunt and Wicks, placing disabled people in a disempowered position. A shift was needed whereby disabled people had input in policy when that policy concerned their welfare. Also, and at a more fundamental level, disabled people, in the opinion of Hunt Wicks and Curry needed to control the organisations that represent their opinions and defend their rights politically.

Disabled people’s organisations shifted from being organised around the good will of others to being constituted to represent the rights and views of the disability community by disabled people themselves. This change occurred as the result of two major shifts in the political landscape. First, a shift in Government policy toward the care of disabled people which meant that for fiscal reasons disabled people were no longer being cared for in large numbers by the state, and second, in the period 1983-1990 the disability rights community was created in New Zealand. Previous organisations for disabled people were reborn as disabled people’s

¹²⁷ Pers Com Robyn Hunt 29 / 3/ 12

¹²⁸ Pers Comm. Robyn Hunt 29 / 3/ 12

organisations; new organisations were created all with the focus of claiming rights for their members equal to the able-bodied community.

The shift from a charity ethic to a citizenship / human rights ethic

A Shift in government policy

Prior to 1975 government policy was based upon the assumption that disabled people should “fit in” to their surroundings, or decently hide themselves away.¹²⁹ In 1972 the Royal Commission into Psychopaedic Hospitals¹³⁰ shifted the Governments policy to one of deinstitutionalisation, whereby patients with disability, particularly intellectual disability were re-introduced back into the community.

This policy shift had a dramatic impact upon members of the intellectual disability community and the organisations who provided the community support services to people with intellectual disabilities and to their families. At that time this responsibility fell largely upon the New Zealand Society for the Intellectually Handicapped (IHC).

The passage of the Disabled Persons Community Welfare Act (DPCW Act) 1975¹³¹ was to signal the beginning of the shift in Government policy toward deinstitutionalisation. This led in turn to a shift in mind set within the disability movement, previously discussed, whereby the movement wanted to assume control for matters that affected disabled people and to assume control of disabled people’s organisations. Both desires were infused by the rise in disability consciousness which occurred as a result of the IYDP in 1981.

¹²⁹ Tennant, M (1996), “Disability in New Zealand: A historical survey” New Zealand Journal of Disability Studies, No.2. p.24

¹³⁰ *Royal Commission into Psychopaedic Hospitals*, Government Printing Office, Wellington, 1972

¹³¹ Measures provided for by the Act included suspensory loans for motor vehicles, short term alternative care for the children of disabled persons, and measures to promote accessibility of public buildings

The 1975 Act provided financial assistance to disabled people living in the community and for disabled people's organisations supporting disabled people living in the community. This assistance was channelled through service agencies such as the charity model based IHC and the New Zealand Society for Crippled Children (CCS).

The Act makes provision for the payment of the cost of alterations to houses. In the case of physical access; ramp access, shower and toilet access to houses. Provision was made within the Act for either persons with disabilities or families or voluntary organisations to request payment to assist with these accommodations. Voluntary organisations were provided with funds under the Act to assess and educate disabled people. No Disabled Persons Organisations (DPO's) were involved with the provision of services.

In the context of accessible access standards, the 1975 Act required that Local Authorities and Councils must ensure that safe passageway is provided for along the street and especially in the area of the kerb.¹³² This provision is of importance to the blind community when crossing the roads and is a key component to making the physical environment accessible.

This example shows that government policy prior to 1972 was predicated upon the underlying imperative that members of the disability community were expected to 'fit it' to the able-bodied world. Within the previous example blind citizens risked physical injury when travelling in and around the city if kerb cuts¹³³ were not present or were reliant upon the goodwill of others to guide them around such obstacles. Another example is physical access to buildings. The 1975 Act provided that Government, local Councils, public companies, or

¹³² Disabled Persons Community Welfare Act 1975 s.24(1)

¹³³ Curb cuts were first instituted for accessibility when the Americans with Disabilities Act (ADA) in 1990 mandated that physical, public locations be accessible for any user. City streets with curbs had to be cut in spots where wheelchair users could move along sidewalks without endangering themselves. Stephanie Roberts "INSTRUCTIONAL DESIGN AND ACCESSIBILITY: COGNITIVE CURB CUTS" University of Northern Colorado, Doctoral Student <http://www.aect.org/Divisions/roberts.htm> Accessed 4/6/12

private individuals must ensure that any building, that they own provide access for disabled people to enter and carry out normal activities.¹³⁴ This provision extended to the inclusion of ramp access and toilet facilities for disabled persons. This provision was not implemented within the Building Act 1955 therefore did not require building owners to implement changes at the point of construction, adding further cost when changes are required to be made after construction.

A rise in group consciousness within the disability community

The blind community provides an excellent example of a politically active community. The very first organisation that represented disabled people in New Zealand was the Association of the Friends of the Blind, formed in 1899 in Auckland. This group was dominated by charitably-inclined friends of blind people and was set up with the purpose to advocate on the behalf of blind people. The First World War led to many servicemen returning with disabilities, blindness among them. From that point priorities shifted, a change in emphasis from advocacy to rehabilitation and reintegration into the workforce.¹³⁵

The Soldiers Civil Re-establishment League, (Rehabilitation League) and later Workbridge was vital in providing these services.¹³⁶ Organisations which were set up to advocate for persons with disabilities, particularly the Blind, in the post war period saw consumer advocate groups dominated by returned servicemen. Organisations for the Blind were particularly prominent for historical reasons; such organisations had been active politically in advocating for pensions

¹³⁴ Disabled Persons Community Welfare Act 1975 s.25(1)

¹³⁵ Catran, K, Hansan, P, *Pioneering a Vision: A History of the Royal New Zealand Foundation for the Blind 1890-1990* (RNZFB, 1992)p.124

¹³⁶ *Ibid*

after both Wars. Pensions for Blind returned servicemen were introduced in 1924 largely due to the efforts and agitation of Clutha McKenzie, a returned serviceman, blinded at Gallipoli.

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The Royal New Zealand Foundation for the Blind,¹³⁸ established on the 9th July 1890 has been for one hundred year the organisation that has provided services for Blind members. The Foundation provided services such as feeding, accommodating, training, all within institutions paid for by the Foundation. In addition, guide dogs and Braille training were paid for as well. The Foundation for the Blind was run for the benefit of blind people by a majority non-blind board and staff. During the period 1970-1980 the Foundation saw a transformation in consciousness with blind members actively seeking to assert control over the running of the Association.

This transformation began with a motion put forward at a conference in Dunedin by Foundation members to recognise the World Charter of the Blind. As a result of the motion, attention was drawn to the World Charter of the Blind which required all service organisations for the blind to provide for adequate representation of blind people elected by blind people.¹³⁹ By 1976 a set of proposals, drawn up by the Association of Blind citizens,¹⁴⁰ a group comprised of blind people exclusively, was presented to the Foundation whereby 50/50 representation of blind and non-blind on the Foundation board was advocated. After discussion with the Minister of Education, who gave the matter further consideration, the

¹³⁷Tennant, M (1996), "Disability in New Zealand: A historical survey" New Zealand Journal of Disability Studies, No.2p.18-19

¹³⁸ Royal New Zealand Foundation for the Blind

¹³⁹ Catran, K, Hansan, P, Pioneering a Vision: A History of the Royal New Zealand Foundation for the Blind 1890-1990 (RNZFB, 1992)p.124

¹⁴⁰ ANBCNZ Association of Blind Citizens New Zealand

Foundation agreed that the representation on the Board of blind members would increase from 14 to 16 but that equal representation would not proceed.

In 1978 the divide between the Foundation and the wishes of the blind community expressed through the Association became public when the Sunday Star wrote an article in which the Board of Foundation accused the Association “of representing a vociferous minority”.¹⁴¹ The period from 1980 onwards was one of “healthy dialogue” between the Association and the Foundation. At the Foundation Conference in 1983 both the Chairmen and Vice Chairmen were blind, easing some of the Association’s previously held concerns over representation within the Foundation. The issues from that point moved on to increased regional trustee representation on the board.¹⁴²

The representation of the dialogue as a ‘healthy dialogue’ indicates an organisational tension almost to the point of internal conflict within organisations formally controlled by non-disabled people. Disabled people at this time were starting to raise questions regarding the running of organisations for their benefit. As the period 1980 to 1990 continued disabled people rejected the concept of being represented by organisations run by non-disabled people. Control within these organisations was reasserted by disabled people. This process indicates the shift in consciousness within the disability community.

Two such examples of this tension are seen in the organisations IHC and CCS. Both are long standing organisations that had been set up by non-disabled people with the intention to

¹⁴¹ Catran, Ken, Hansan, Penny, *Pioneering a Vision: A History of the Royal New Zealand Foundation for the Blind 1890-1990* (RNZFB, 1992)p.124

¹⁴² Newbold, G (1995). *Quest for equity : a history of blindness advocacy in New Zealand* Palmerston North, N.Z. : Dunmore Press p.150,

benefit the disabled community through the doing of 'good works'. The period 1981-1990 would witness stress within both organisations with regard to the role played by non-disabled people within both organisations.

New Zealand Society for the Intellectually Handicapped (IHC)

The figurehead of the intellectual disability community in New Zealand in the period 1980 to 1990 was J.B. Munro. Munro was elected national executive director of IHC in 1976. Active in politics in Invercargill, he ran for elected office for the Labour Party and was elected as the member for Invercargill from 1972–1975, after serving one term in Parliament during which time he shepherded the DPCW Act 1975 through parliament, after leaving parliament he became an Invercargill City Councillor.

Munro also had lived experience of disability having contracted polio very early in life which affected his left leg, leaving him unable to walk. Until the age of three he ambulated with the aid of a calliper. Munro's polio resulted in his having to have several operations at Dunedin Hospital to straighten his leg. He was able to walk without the calliper by the age of 16 through his own effort but this experience gave him an appreciation of disability that he would carry with him his whole life. Munro also had experiences of disability through his brother who was in a wheelchair, but his exposure to intellectual disability came through his experience with a boy with Down syndrome.

The period from 1980 onward was one of huge upheaval for the intellectual disability community. The Government pursued a policy of 'deinstitutionalisation' which resulted from the 1972 Royal Commission into Psychopaedic Hospitals.¹⁴³ This policy led to the practice of

¹⁴³ Royal Commission of Inquiry into Psychopaedic Hospitals, Government Printing Office, Wellington, 1972

‘normalisation’, whereby from 1974 mildly and moderately-disabled people were discharged into the community.

IHC developed the concept of ‘shared care’ to cope with the large influx of people with intellectual disabilities being discharged, a process that the disability movement was wholly supportive as it achieved one of the key aims within the community of self-determination. The resulting movement of people with intellectual disabilities from institutions back into the community and into their homes placed huge stress upon the families of the intellectually disabled children and adults coming back into familial care.

The changes enforced by the Government to deinstitutionalise the care of intellectually disabled people:

“owe as much to the government’s desire to cut the costs of maintaining the institutions as to a recognition that institutions were not the best place for many people”.¹⁴⁴

Regardless of the Governments rationale for pursuing the policy, IHC had to develop the methods and infrastructure to help families care for their children and young people being sent back home. IHC became very involved in advocating on their behalf.

The creation of organisations such as People First¹⁴⁵ in the 1980s is significant as it represents an organisation for the first time was run by people with intellectual disabilities. People First represented the views of the intellectual disability community. People First is an organisation staffed and run by people with intellectual disability, not an organisation run for the benefit

¹⁴⁴ Millen, Julia Breaking barriers : IHC's first 50 years Wellington, N.Z. : IHC New Zealand,

¹⁴⁵ <http://www.peoplefirst.org.nz/Home/tabid/36/Default.aspx>

of people with an intellectual disability by non-disabled people. It signifies the shift away from the IHC model of representation toward a more rights-based approach.

New Zealand Crippled Children's Society (now CCS Disability Action)

The New Zealand Crippled Children's Society¹⁴⁶ (NZCCS) was established in 1935 in the aftermath of polio epidemics in 1916, 1924 and 1925. The purpose of CCS was to help children afflicted by polio or other disabling conditions.

During the period of 1980 – 1990 CCS was an organisation that provided services, support and advocacy through programmes to the disability community. IYDP telethon raised a total of \$6 million. \$42 million worth of applications were received; the society received \$225,600, which was in the society's view "disappointing... or less than 4% of the total telethon grant."¹⁴⁷

CCS advocates for accessible environments for its clients to be able to use in their daily life. The CCS Barrier Free Programme is an example of CCS partnering with Fletcher Residential to build a residential home accessible to people with a disability.

The Barrier Free Programme project was designed to construct a barrier free home, built by private sector Company, Warner and Masters, who constructed the fully accessible home. The project represented the first time that a major New Zealand construction company had adopted accessibility into its design processes and opened up further consultancy opportunities in the 'universal design' sector. The House was officially opened by the Prime Minister in October 1982.¹⁴⁸

¹⁴⁶ Now CCS Disability Action

¹⁴⁷ CCS Organisational History: the first Fifty Years CCS, 1984

¹⁴⁸ CCS Organisational History: the first Fifty Years CCS, 1984

A major part of the work CCS does is to normalise disability in the community for both disabled children and non-disabled children. In furtherance of this aim CCS adopted the 'Kids up the Road' puppet education programme, funded through a telethon grant and launched in February 1982. The project was taken from a project in Washington, USA whereby puppets are used to achieve the basic aim of facilitating integration and extending knowledge of disabilities by children in schools who do not have disabilities. Some of the disabilities highlighted included cerebral palsy, spina bifida, blindness, deafness and intellectual disability. The programme was viewed by 69,000 children aged between 8-10 years old and on television by 431,000 young people.

CCS was also involved in the production of two successful films. The first "Fun Gap" was the National Film Unit's contribution to IYDP. The film was contracted by the Council for Recreation and Sport¹⁴⁹. "The film depicts disabled people in participating in recreation and sport showing what is possible with a little understanding and support. "¹⁵⁰

The second film "Like you" contrasts the life of an able-bodied teenager with that of her disabled twin with cerebral palsy. The film shows the "courage and stamina needed to be a disabled teenager, but also how with understanding and support disabled people can achieve a full and satisfying lifestyle".¹⁵¹ Both films were shown at the International Rehabilitation Film festival Awards and on New Zealand television.

¹⁴⁹Now SPARC

¹⁵⁰ CCS Organisational History: the first Fifty Years CCS, 1984

¹⁵¹ *Ibid*

The second major event to occur in the wake of the 1981 IYDP was the coming together of groups of disabled people. The Auckland Co-ordinating Council for the Disabled, the New Zealand Council for the Disabled Persons Incorporated (DPI), combined groups of disabled people with groups for disabled people to form the Disabled Peoples Assembly (NZ) on the 26th February 1983. The relevance of the event was that these groups were controlled by disabled people and the new organisation they were meeting to create would be controlled by disabled people as well.

The creation of DPA

DPA's history begins with friction between disability groups over the issue of whether to form a national organisation to represent Rehabilitation International (RI) in New Zealand. The meeting was called in November by the Crippled Children's Society. The other major interest represented was the New Zealand Council for the Disabled, previously established on the 9th December 1978.

The Council advocated being the New Zealand representative for RI, this was not successful. Possible explanations for the resolutions lack of success include a feeling among members that the Council did not permit smaller members into the Council and that the Council was too influenced by "Consumer interests."

The standing committee (RI NZ) which had worked on organising IYDP within New Zealand formed a foundation upon which national and international representation of people with disabilities could be based. With this in mind a series of meeting were held in 1982 between

RI NZ and the NZ Council for the Disabled. The consensus at these meetings was affected by the major division that occurred at the Winnipeg Conference and the subsequent creation of Disabled Peoples' International (DPI), creating an organisation that spoke for people with disabilities at both the national and international level.

On the 21st March 1983 at an extraordinary General Meeting held at a Conference of the New Zealand Council for the Disabled in Hamilton, the organisation amended its Constitution to change its name from the New Zealand Council for the Disabled Incorporated to the Disabled Persons Assembly (DPA) (New Zealand). ¹⁵²

The Constitution was amended, including a new set of rules governing running of the newly-named organisation. The most relevant rule change related to the structure of the organisation, requiring a 51% majority of disabled members at all times.

As a result, the new organisation, DPA (New Zealand) elected a board comprising of Paul Curry, John Stott and Byron Buick-Constable. The board then hired Dave Henderson to administer the Total Mobility scheme which had been funded through the allocation of funds as a result of telethon. Henderson came to DPA from the Auckland Regional Council where he had been a transport planner. This experience and skills in planning made Henderson valuable to DPA despite his being non-disabled, Henderson was able to manage the nationwide Total Mobility scheme.

As someone without a disability, Henderson, represents somewhat of an anomaly at the time when DPA was becoming politically very disability-focussed. Henderson would go on to develop a partnership with long serving DPA lawyer Quentin Angus that would mark DPA's

¹⁵² Newbold, G (1995). Quest for equity : a history of blindness advocacy in New Zealand Palmerston North, N.Z. : Dunmore Press. P.160

lobbying in the late 1980s. Henderson describes the way that key figures within the disability community; Russell Kearsse at CCS, Paul Curry and the Ministry of Health during the period of the late 1980's began to demand that things changed, particularly with reference to Paul Curry at Health, saying that:

“Curry was not prepared to accept the way that systems were.”¹⁵³

Curry argues that old systems, particularly health related systems, which had historically been set up with primarily the system in mind, ‘had to change’. In support for Curry’s contention, Munford argues:

“Historically, people with disabilities have been assessed, ranked and classified. These procedures have not always resulted in the provision of inclusive services but services that have excluded individuals from the mainstream.”¹⁵⁴

In 1989 Henderson was made CEO of DPA. Henderson received the news, while he was flying back from Sweden that DPA CEO Ken Munro had died. Upon his arrival two events occurred. First, Henderson was interviewed for the role by DPA Board chair Marilyn Blaikie, and second, Quentin Angus proceeded immediately into DPA offices to prepare select committee submissions that had long sat on his desk. Posthumous DPA Chief Ken Munro had not been an advocate of legislative change. In Henderson, Angus saw an ally and the two formed a partnership that Henderson describes as “a great partnership that lasted the rest of Quentin’s life.”¹⁵⁵

¹⁵³ Pers comm. Dave Henderson 21/3/12

¹⁵⁴ Munford (1994) *Caregiving - 'a shared commitment'* in Ballard K (Ed) *Disability, Family, Whanau and Society*, (Palmerston North, Dunmore Press)

¹⁵⁵ Pers comm. Dave Henderson 21/3/12

Both Henderson and Angus realised that legislative change had to occur, and that in the words of Henderson “if they didn’t change the law of the land, discrimination wouldn’t change with education campaigns alone.”¹⁵⁶

Together the two campaigners began to get submissions to select committees that related to disability issues, they appeared in front of Committees hearing bills that related to disability issues to argue their case with the purpose of getting amendments and clauses inserted into Bills that addressed the rights of disabled people. There was no legislative strategy being applied by the two at this point; both campaigners were determined to get the disability issue in front of select committees as often as possible. Henderson recalls that Angus had “drafted submissions on anything that affected disability”¹⁵⁷ and the two would appear in person to argue their case in front of select committees.

All the writing and presenting of submissions on disability related bills laid the ground work for the first big test of the lobbying ability of DPA. That first big test was to come when the New Zealand Bill of Rights Bill went before select committee in 1989. The bill was drafted in 1985 by Attorney General and Minister of Justice Sir Geoffrey Palmer. The country was facing an election in 1990. As it turned out, Sir Geoffrey Palmer was Prime Minister during the bill’s passage through select committee, but would be succeeded by Mike Moore by the time bill was passed into law.

DPA would be tested in terms of its ability to navigate through the legislative process, gain access to the key people responsible for passage of the Bill and to put successful arguments in front of those people. The Bill of Rights campaign would be the first test of DPA’s ability to

¹⁵⁶ *Ibid*

¹⁵⁷ See note 135

make clear the frustration of the disability community and to assert that only legislative change would end discrimination.

Chapter 5 Disability discrimination and the New Zealand Bill of Rights Act 1990

The New Zealand Bill of Rights Act 1990 was the first major piece of legislation the DPA attempted to influence through the lobbying process. Prior to 1990 DPA had lobbied Parliament piecemeal style attempting to gain the inclusion of disability amendments into enactments, but nothing as large as the bill of rights had been taken on by DPA prior to 1990. This chapter outlines the lobbying process that DPA took attempting to get disability included as a ground of discrimination that, as a group, disabled people had a right to be free from.

The chapter begins by outlining the process that the Bill of Rights 1990 went through as it proceeded from white paper to select committee to the final law passed by Parliament on 28th August 1990. The chapter demonstrates that the purpose of the bill was to restrain the power of the State. This purpose, it will be argued, runs counter to the argument that DPA was advancing within its submission to Parliament which was to extend the duties placed upon the state as contained within the Declaration on Economic Social and Cultural Rights.

The chapter outlines the lobbying that DPA attempted to carry out to include disability discrimination within the Bill of Rights and argues that DPA were unsuccessful for two main reasons. First, the major state actor behind the bill, Palmer did not see disability

discrimination as coming within the scope of the bill and second, the Bill was rushed through the Parliament before a general election, resulting in key elements of the Bill being sacrificed to get the bill through the Parliament.

The White Paper on a Bill of Rights for New Zealand¹⁵⁸ was tabled in Parliament on 2nd April 1985. This was the first step in the legislative process that would culminate in the New Zealand Bill of Rights 1990. As is typical, the draft Bill, was sent to select committee.

The Bill contained two particularly controversial draft clauses. First the bill of rights would become entrenched 'supreme' law that would require a 75% majority of Parliament to alter, against which all other legislation would be tested in the Courts. Second; the *Treaty of Waitangi* was to be included under Article II of the bill where the rights of Maori were to be 'recognised and affirmed'.¹⁵⁹ The insertion of these two clauses would capture both the attention of the legal community and the public during the select committee phase of the Bill. The fact that these two controversial aspects were to be included meant that a protracted consultation process was needed before the legislation could be passed through the Parliament.

The Bill of Rights within select committee

The Justice and Electoral Law Reform select committee heard submissions from Tuesday 11th February 1986 till Tuesday 9th December 1986. Of the 431 formal submissions that were formally received, 107 were oral and 304 were written submissions. 62 hours and

¹⁵⁸ A Bill of Rights for New Zealand: A White Paper Presented to the House of Representatives by Leave of the Hon. Sir Geoffrey Palmer, Minister of Justice. Government Printer, Wellington, New Zealand 1985

¹⁵⁹ Ibid at p 74-77

35 minutes of oral evidence was heard by the committee as it travelled to Wellington, Hamilton, Auckland, Tauranga, Christchurch, and Dunedin to hold hearings.

At the end of the select committee hearings an Interim Report and then a Final Report were produced. A Department of Justice Report was sought and tabled within the select committee answering two questions first, whether there was a need for a Bill of Rights and second, whether there was a need for a Bill of Rights to be entrenched. All reports were submitted to the Justice and Electoral Reform Committee.

As Palmer made clear within the White Paper, the Bill of Rights was enacted to counter a view, expressed through the White Paper by Palmer himself that the powers of Parliamentary Supremacy were too great, giving the Parliament too much power to legislate without the scrutiny of one other branch of Government, the Judiciary. This concern led Sir Geoffrey Palmer to coin the phrase, the 'fastest democracy in the west'¹⁶⁰ with regard to the legislative process within the New Zealand Parliament. His intention for the bill, as expressed within the White Paper was to "improve the system of government in New Zealand".¹⁶¹ Palmer believed that providing greater constitutional safeguards in the form of protections for fundamental rights and freedoms was "vital to the survival of New Zealand's democratic and multicultural society".¹⁶²

By restricting the power of the state, Palmer wished to place clear limitations upon such State actions as: arbitrary arrest, illegal search and seizure, and holding without warrant. The

¹⁶⁰ Palmer, G.W.R *Unbridled Power: an interpretation of New Zealand's constitution & government*, Auckland, N.Z.: Oxford University Press, 1987.

¹⁶¹ *A Bill of Rights for New Zealand: A White Paper Presented to the House of Representatives by Leave of the Hon. Sir Geoffrey Palmer, Minister of Justice*. Government Printer, Wellington, New Zealand 1985 p.5

¹⁶² *ibid* pg. 5

safeguards outlined in the white paper took the form of empowering the Courts to scrutinise laws that Parliament passed against a standard as set by the bill of rights. This was a controversial concept to many in New Zealand at the time the white paper was tabled as it challenged the supreme authority of Parliament to pass laws. Rishworth comments upon the mandate of the Labour Government to pass the bill:

“The labour Justice Minister [Palmer] was personally committed to the idea of a Bill of Rights, took the view, however that Labour only had a mandate to enact one as an ordinary statute”¹⁶³

Palmer’s view over whether an entrenched bill of rights was necessary had evolved over time. Initially in the 1968 essay “A Bill of Rights for New Zealand?” he argued that:

“... an entrenched Bill of Rights would be a dangerous idea due to the fact it would place the judiciary into a political situation”¹⁶⁴.

This opinion changed as a result of his spending time in the United States studying the US bill of rights. Palmer came to the conclusion that

“.... there was majoritarian discrimination against minorities... and that the fabric of society requires that their special interests be protected and even from the legislature exhibiting the prejudice of the majority.”¹⁶⁵

Of the 431 submissions received by the select committee 78 related directly to whether the final bill should become entrenched law. 23 submissions were supportive of the Bill becoming entrenched, 23 were opposed, 25 neither supported nor opposed entrenchment and 7 expressed no opinion either way.¹⁶⁶

¹⁶³ P Rishworth, et al (2003) *The New Zealand Bill of Rights* Oxford University Press, Melbourne,

¹⁶⁴ Palmer, G (1992) *New Zealand’s Constitution in Crisis*, McIndoe, Dunedin, p.54

¹⁶⁵ *Ibid* at 54

¹⁶⁶ Hansard, 17 July 1990, 2799

The second major area that the white paper advocated was to include the Treaty of Waitangi within the Bill of Rights. Palmer was supportive of incorporating the Treaty of Waitangi within the bill of rights. At a meeting of Maori tribal elders, held in 1986 “it was argued that incorporating the Treaty of Waitangi into a Bill of Rights would diminish the status of the Treaty as the founding constitutional document of New Zealand and allow Parliament to amend the Treaty without the consent of the Maori treaty partner.”¹⁶⁷

Indicating that support for an entrenched treaty provision was not present the National Party removed its support from the Bill. Palmer comments upon the impact of that decision, “Basic constitutional change really does need widespread political support if it is to succeed.”¹⁶⁸

These ideas would be fought out during the select committee process, resulting in a Final Report, tabled in Parliament on 9 July 1987, with the final Act not being passed until 28 August 1990.

The Interim Report

The interim report ¹⁶⁹ of the Justice and Law Reform select committee stated that a majority of submissions to the select committee were opposed to the bill of rights as the bill was drafted in select committee. The primary reason given in written and oral submissions for opposing the bill was that laws could be challenged in the Courts against a standard set by the bill of rights. The bill would shift power away from the legislative branch of government, an elected body, to the non-elected judicial branch; the effect of this shift was to make the Parliament no longer the supreme law-making body as it is under the Westminster system of democracy.

¹⁶⁷ Mapp, W(1994) “New Zealand’s Bill of Rights: A Provisional Assessment Agenda Vol 1 No 1, p. 82

¹⁶⁸ See note 143 at 57

¹⁶⁹ Opposition to the Bill stemmed from one of the key recommendations of the Bill of Rights as drafted in committee stage, to enact the Bill as an entrenched piece of legislation.

In submissions supporting the bill the reasons given for were the lack of constitutional safeguards in New Zealand against abuses perpetrated by the executive or legislative branches of government, and that minorities and disadvantaged groups needed greater protections¹⁷⁰, that the educative effect of the bill would be beneficial to society, and would act as a bulwark against an erosion of rights, and that a bill of rights is consistent with New Zealand's international obligations, for example; The International Convention on Civil and Political Rights, ICCPR.¹⁷¹

During the submission process, members of the select committee noted:

“that the committee was disappointed with the general lack of knowledge of the public concerning the issues under consideration as well as the lack of vigorous debate over the issues from which the people of New Zealand could learn of the bill's effects”.¹⁷²

This view was shared by Palmer who commented that “only 6% [of the NZ Law Society] considered they had a comprehensive knowledge of the bill”.¹⁷³

The Ministry of Justice Report

A report was prepared by the Ministry of Justice to answer the question of whether there was a need for the proposed bill of rights and additionally whether it was necessary for the bill to become entrenched or supreme law.

The report from the Ministry of Justice concluded that there was substantial merit in the bill of rights. This was based upon three arguments, first, that existing checks upon the powers

¹⁷⁰ This was the argument that Dave Henderson for DPA advanced unsuccessfully in the lobbying for the Bill of Rights to Sir Sir Geoffrey Palmer.

¹⁷¹ Interim Report to the Justice and Electoral Reform Committee On a White Paper on a Bill of Rights for New Zealand pp.14-22

¹⁷² Interim Report, p.3

¹⁷³ Palmer, G.W.R New Zealand's constitution in crisis : reforming our political system (Dunedin, N.Z. : McIndoe, 1992) p.56

of the executive were minimal, second, that a bill would allow New Zealand to comply with International obligations in the form of the ICCPR¹⁷⁴ and third, that it would have substantial implications as an educational tool.¹⁷⁵

The Ministry of Justice supported the conclusions of the final report of the select committee by recommending the creation of a non- judicially enforceable Bill.¹⁷⁶ The Ministry of Justice advised that, in light of the standard of submissions received by the select committee there was also a need for the bill to be explained to the public in greater detail.

The Final Report

The Final Report, tabled in Parliament on the 9th July 1987, concluded that:

“New Zealand is not yet ready, if it ever will be, for a fully-fledged bill of Rights along the lines of the white paper draft.”¹⁷⁷

The committee took as evidence, a lack of understanding of, and support for, the judiciary in the bill of rights, combined with the community’s lack of knowledge of fundamental human rights to reach the conclusion that there was no need to recommend a fully entrenched bill.

The final report recommended the inclusion of economic, social and cultural rights, this was included after numerous submissions were received arguing that these rights are as equally important as civil and political rights.

Palmer had a particular view as to the purpose of the bill of rights bill. His view was that the bill was intended to restrain the power of the executive by providing checks and balances on

¹⁷⁴International Covenant on Civil and Political Rights, ratified by General Assembly resolution 2200A (XXI) of 16 December 1966. Entry into force 23 March 1976, in accordance with article 49.

¹⁷⁵ See note 9 pp. 14-22

¹⁷⁶ See note 9 at pp. 80-83

¹⁷⁷ Final Report to the Justice and Electoral Reform Committee On a White Paper on a Bill of Rights for New Zealand at pp. 3

the ability of the state and state actors to exercise power. The legislation, in Palmer's view discharged state power in a negative manner by stating what the executive may not do, in relation to civil and political rights, life and security of the person, non-discrimination, unreasonable search and seizure, freedoms of religion, expression, minority rights, and minimum standards of criminal procedure.

Purpose of the legislation

The New Zealand Bill of Rights Act 1990 was passed with the purpose of "regulating and limiting the power of government and public actors."¹⁷⁸ The act was clearly passed with the actions of the Crown in mind.

Section 19 confers a right to be free from discrimination on the following grounds: race, ethnic or; national origins, sex, marital status, or religious or ethical belief. When the Act was passed disability was not included within the grounds of discrimination to which protection was granted.

Two important aspects to the drafting of the Bill of Rights are worthy of noting that have bearing upon the non-inclusion of disability within s.19.

Sir Geoffrey Palmer, who largely drafted it, stated that to broaden the bill of rights so that it encompassed policy questions such as the right to work, to housing, to education and to adequate healthcare:

"Made it unmanageable in my view, and opened it up to ridicule."¹⁷⁹

Palmer also stated "that to claim as fundamental rights, matters which are not within the power of the government to deliver would cause expectations to rise, only then to be

¹⁷⁸ "Re-evaluation of the Human Rights Protections in New Zealand" (Oct 2000, Ministry of Justice)

¹⁷⁹ Palmer, G.W.R New Zealand's constitution in crisis : reforming our political system (Dunedin, N.Z. : McIndoe, 1992) p.57

dashed”.¹⁸⁰ The view that to include economic and social rights within the Bill of Rights would ‘make it unmanageable, did not receive universal support’.

Shaw and Elkind argue in support of the economic and social rights (ESR) by pointing out that the balance of power between the individual and the state is heavily weighted on the side of the State, and that the purpose of a bill of rights is to protect minority rights, (this is the argument that Palmer supported in the white paper but limited it to the protection of Maori) when in the words of the authors “the principles of human rights can often be ignored by the State”.¹⁸¹

Elite support

Palmer had expressed views on the inclusion of economic, social and cultural rights that were known to the disability community prior to the bill going before Parliament. According to Dave Henderson, past CEO of the DPA, Palmer’s view on the inclusion of economic and social rights were well known, “he didn’t buy it.”¹⁸² Palmer was convinced that the Government should not be made liable for ‘quasi policy’ outcomes.

What did Palmer mean by a ‘quasi policy’ outcome? He is referring to the right to employment, to a house, or to healthcare. The concern was that by creating an obligation to provide these outcomes the government could be litigated against for the failure to provide employment, or housing, or to provide healthcare when the provision of these outcomes falls outside the ability of the government to deliver.

Dave Henderson suggests that Palmer’s view of the inclusion of economic, social and cultural rights was that to include an onus upon the state to take positive action would take New

¹⁸⁰Palmer, G.W.R New Zealand's constitution in crisis : reforming our political system (Dunedin, N.Z. : McIndoe, 1992) p.57

¹⁸¹ Shaw and Elkind, A Standard for Justice, OUP, Auckland, 1986

¹⁸² Pers comm. Dave Henderson 21 / 3 / 12

Zealand in the direction of affirmative action, which Henderson suggests was a ‘huge political football’ and in his view Parliament saw no need for that move at the time.¹⁸³

In his time in the United States as a Professor of law at Iowa State University, Palmer had been influenced by the American Bill of Rights model as a blueprint to restrain the power of the state. He saw New Zealand as becoming an increasingly pluralistic society where minority groups would need a form of protection against discrimination from the majority.¹⁸⁴ Palmer however, did not extend the argument with relation to minority groups any further than to Maori. To do so, he argued, would open the debate up to the possibility of inclusion of rights that would challenge the purpose of the legislation, which was, to restrain state power.

Economic Social and Cultural Rights

The select committee’s final report noted that a number of submissions had been received in support of the inclusion of economic, social and cultural rights, supporting the international commitment by New Zealand to the International Covenant on Economic, Social and Cultural Rights (ICESCR).¹⁸⁵

The Social Responsibility Commission of the Anglican Church of New Zealand argued in a submission to the select committee that “questions of health, security of income and employment, welfare, education, and housing are far more immediate than the right not to be tortured or rights under the criminal justice system”¹⁸⁶. The submission argued that “if all

¹⁸³ *ibid*

¹⁸⁴ The arguments that Palmer made with reference to minority groups and protection from discrimination were exclusively made with reference to Maori See Palmer, G.W.R New Zealand’s constitution in crisis : reforming our political system (Dunedin, N.Z. : McIndoe, 1992) p.52

¹⁸⁵ Signed 12 Nov 1968, Ratified 28 Dec 1978

¹⁸⁶ Submission of The Social Responsibility Commission of the Anglican Church of New Zealand to the Select committee on Justice and Law Reform Submission no.42 para.6.3

the rights are not included there could be a real danger of courts being forced to give meanings to enactments which are inconsistent with basic rights and freedoms".¹⁸⁷

In a submission equally supportive of the inclusion of economic and social and cultural rights the group The 'Shelter For All' Coalition submitted that "the right to adequate housing is a principle enshrined within Article 25 of the UN Declaration of Human Rights"¹⁸⁸. Further, the group argued that "within a generally accepted hierarchy of needs food, clothing, shelter and health take precedence over political freedoms ... of what use is, for instance the right to be free from unreasonable search and seizure for someone who has no home from which to be searched ... freedom of association rings hollow in the ears of those forced by economic circumstances to share accommodations with strangers".¹⁸⁹

The select committee decided to support a provision including economic, social and cultural rights within the draft Bill. Despite the committee's recommendation the final bill did not include economic, social and cultural rights. Richard Northey, chair of the Caucus Justice Committee, commented in Parliament upon the reasons for the non-inclusion of economic, social and cultural rights within the final draft:

"it has been omitted because the belief is that the bill should be concentrated upon matters that do not have resource implications." ¹⁹⁰

Another possible explanation for the non-inclusion lies in the timing of the passage of the bill. The bill of rights was assented by the Governor General on the 28th August 1990; the general election was less than two months away, in October of that year. The likelihood of a third term for the Labour Government after 1990 was slim. Knowing this, Palmer had two options, first, to pass a version of the bill before the election in whatever form could get through the

¹⁸⁷ *Ibid*

¹⁸⁸ Submission of the Shelter For All Coalition to the Select Committee on Justice and Law Reform, 9 November 1989 Submission No.8

¹⁸⁹ *Ibid*

¹⁹⁰ Hansard, 17 July 1990 2804

House in the time remaining before the election, which would mean sacrificing some of the aspects of the bill, such as an expanded rights protection, or second, delay to include the expanded rights, such as economic, social and cultural rights and risk sacrificing the Bill in its entirety. Palmer chose to get the legislation through the house, in the form that it is currently represented in the statute books, without a supreme law component and without reference to economic, social and cultural rights.

Palmer had prior to its introduction to Parliament, expressed his unwillingness to include economic and social rights within the bill. The select committee, after receiving submissions supportive of economic and social rights included the rights in part II of the bill. However, the timetabling of the bill in Parliament with relation to the impending election and the view that Palmer took regarding economic and social rights were to significantly dampen any effect that DPA could and would make around the inclusion of disability into the bill of rights.

DPA's lobbying for the inclusion of disability into the Bill of Rights Act 1990

In 1989 DPA as an organisation was led by Dave Henderson. Henderson recalls the lobbying effort DPA made to include disability within what would become s.19 of the Bill of Rights. DPA argued that a 'whole of society approach was needed when dealing with people that faced significant disadvantage. In Henderson's opinion, the disability community did face significant disadvantage'.¹⁹¹ Henderson recalls DPA's argument that:

“government has a greater responsibility to ensure participation in society for groups that face ‘significant barriers to participation’”.¹⁹²

¹⁹¹ Pers comm. Dave Henderson 21 / 3 / 12

¹⁹² Disabled Persons Assembly Submission to the Select Committee on Justice and Law Reform Submission no.9 p.2

DPA's submission to the Justice and Law Reform select committee advocated the adoption of a clause similar to the Canadian Charter of Rights and Freedoms, stating that everyone has the right to be free from discrimination.

Further DPA's submission argued that any onus placed upon disabled people to establish a breach by the Crown would place:

“... additional onus upon those who are least able to bear the added stigma.”¹⁹³

DPA's position is clearly opposed to the argument being advanced by Palmer who argued that a bill of rights is necessary to restrain state power, that the law is necessary to prevent the state from doing certain things.¹⁹⁴ Palmer argued that the state or the government must not do such things as: hold citizens without a legal warrant, or conduct an illegal search or seizure.

DPA argued for the complete opposite, for a requirement for positive action on the behalf of the State, for it 'to do something'. DPA wanted the rights contained in the United Nations Covenant on Economic and Social Rights to be included within the bill of rights. This would have included such rights as, the right to food, shelter, education, healthcare and work. These are the same rights as were originally included within the UNSR Rules 1-12 which outlines the 'Preconditions for equal participation' and the 'Areas for equal participation.'¹⁹⁵ UNSR Rule 15 creates the obligation for member states to pass disability discrimination legislation. Both the UNSR and the UN Covenant on Economic and Social Rights contain economic and social rights. These two documents formed the basis for DPA's submission that economic and social rights be included within the bill of rights.

Disability community reaction

¹⁹³ *Ibid*

¹⁹⁴ Such as illegal search and seizure, holding somebody without an arrest warrant,

¹⁹⁵ <http://www.un.org/disabilities/documents/gadocs/standardrules.pdf> accessed 2/8/12

Wendi Wicks was secretary of DPA Wellington office at the time the bill of rights became law. In Wick's recollection, the bill of rights received a 'muted' reaction within DPA, a view shared by Anne Hawker, DPA national president at the time.¹⁹⁶ A potential explanation for this reaction within the disability community is provided by Hawker, who suggests a lack of understanding within the community about the issues contained within the bill of rights. In Hawker's view the disability community did not "unpack the legislation."¹⁹⁷

This lack of knowledge within the disability sector was to be later confirmed when DPA commissioned research. In 2007 the United Nations combined both civil and political rights and economic and social rights into the Convention on the Rights of Disabled People (CRDP) which was ratified by the New Zealand Parliament on the 25 September 2008. Hawker argues that the disability community did not understand the legislation. This is in Hawker's view, further emphasised, by her ¹⁹⁸ illustration with an example of when an education campaign was started around the Convention on the Rights of Persons with Disabilities (CRPD). DPA found that there were large gaps in knowledge within the community on the role and application of the CRPD. This highlights a lack of connection between the Convention and the daily lives of disabled people.¹⁹⁹ This knowledge gap was also evident in the lead up to the passage of the bill of rights.

The disability community, DPA, in particular, failed to understand the significance of economic and social rights potentially having legislative form together, within the bill of rights debate in 1990. Hawker puts the lack of unpacking the Bill down to a 'sector immaturity' within the

¹⁹⁶ Pers comm. Anne Hawker 28 / 3 / 12

¹⁹⁷ *Ibid*

¹⁹⁸ <http://www.un.org/disabilities/countries.asp?navid=12&pid=166#N> Accessed 2/4/12

¹⁹⁹ The lack of sector knowledge is a long standing issue and concern, highlighted in interviews with Anne Hawker and Wendi Wicks

disability community'. Within this broad sweeping comment lies a commentary from Hawker, who had spent many years working within the disability community, initially locally in Dunedin for DPA, then nationally as president of DPA about how the organisation was inward looking at that particular time and did not take a strategic view about legislative change.

This lack of understanding about the potential impact of the legislation and about constitutional law matters generally was not confined to the disability community. Both Sir Geoffrey Palmer and the Justice and Law Reform select committee which drafted the White Paper "A Bill of Rights for New Zealand had noted the "general lack of knowledge about the issues being debated".²⁰⁰ However it seems the disability community was slow to grasp the importance of the legislation.

A possible reason why the disability community did not unpack the legislation is provided by Wendi Wicks, DPA Wellington Secretary. Wicks argues that for DPA, the bill of rights debate was not a 'hot button' debate. "Nobody had taken the time to understand the implications of the bill for the wider disability community."²⁰¹ For Wicks the Bill of Rights debate was being conducted at a very high level, largely on a legal / political level. Submissions to the Justice and law Reform select committee reflect that the general public, the disability community inclusive were not engaged in the debate. Wicks sums up the feeling within the disability community regarding the lack of enthusiasm over constitutional matters: "Constitutional law doesn't get people excited."²⁰²

For Wicks, to get the disability community excited about a legislative issue required connection to a larger discrimination narrative within the community that could be used as

²⁰⁰The New Zealand Bill of Rights Act 1990: A step towards the Canadian and American examples or a continuation of Parliamentary Supremacy? PhD Thesis, (1992) Michael Luis Principe, University of California, Santa Barbara.

²⁰¹ Pers comm. Wendi Wicks 27 / 3 / 12

²⁰² *Ibid*

fuel for a campaign for legislative change. Wicks sums up the difference here, the bill of rights campaign was not focussed on allowing access for disabled people to transportation, to housing or to public buildings. It was not focussed upon discrimination protection within the workplace, places of recreation and housing. Instead it was a piece of legislation intended to restrict the powers of the state.

These comments from Hawker and Wicks relating to why DPA did not make more of the opportunity around the Bill of Rights point to several key factors about the disability community at the time. Disabled people were focussed upon defining themselves as people, and making their way in a world that was a struggle, continual energy had gone into identifying as a disabled person and identifying with a disabled persons organisation that coherently represents each person. This inward organisational focus meant that as disabled persons organisations were less focussed upon issues such as educating memberships on relevant political matters such as the debate around inclusion of disability into the Bill of Rights. Hawker's comment that the disability community did not unpack the Bill of Rights is correct but was not aided by a lack of leadership from the disability organisations by not leading an information process within the disability community. While Wicks correctly assess that constitutional law doesn't get people excited the leadership exhibited by DPO's could have made issues relevant and interesting for disabled people.

The passage of the Bill of Rights Act 1990 could be viewed as a missed opportunity from a lobbying perspective for DPA. DPA did not gain a disability amendment within section 19 of the Bill. Dave Henderson's interactions with Sir Geoffrey Palmer did not result in economic social and cultural rights being included within the bill. From a purely objective perspective DPA did not gain a lot from the 1990 campaign. What DPA did gain from the campaign was a

sense of urgency, that if they did not take the next opportunity, if another bill was to come before Parliament, all opportunity would be lost, to secure legislative protections for people with disability.

The chance to pass a piece of legislation that would make it illegal to treat people with disabilities differently was such a hot button issue for the disability community that the whole community became engaged just two years later in 1992 with the discussion of a separate Human Rights Act. Parliament's consideration of this piece of legislation would give advocates an opportunity to tell the stories of a lack of participation within society, of discrimination, of rejection with no basis for redress, stories that had been stored up for a generation and longer.

The next chapter describes the legislative pathway from the Race Relations Act 1971 to the Human Rights Act 1993, it outlines a key piece of work that DPA needed to do prior to any substantive lobbying regarding the distinction between legal and illegal discrimination. It shows that when faced with the prospect that disability protection would not be included within the Human Rights Act 1993, the disability community was energised to begin a lobbying effort based upon the 'common ground' of discrimination. This was not without complications however. There was an intense internal struggle within DPA over whether to collaborate with the Aids Foundation (AF) in favour of a broad disability clause that would also protect people with HIV/Aids, or whether to advocate for a disability-specific provision. The chapter concludes with remarks about what made the campaign successful.

Chapter 6 The disability clause, lobbying and the Human Rights Act 1993

This chapter focuses upon the lobbying by the DPA and the AF who joined forces to get Parliament to pass an expanded disability definition clause as an amendment to the Human Rights Act 1993. The chapter begins by outlining the legislative history of the Human Rights Act 1993, beginning with the Race Relations Act 1971, the Human Rights Commission Act 1977, and finally with the passage of the Human Rights Act 1993. The chapter moves on to discuss work DPA conducted with the Human Rights Commission to counter the lobbying from the Insurance sector, relating to legal and illegal discrimination and proposed exceptions to the 1993 Act.

The primary focus is the lobbying that took place to secure inclusion of a disability clause within the Human Rights Bill 1993. The chapter details the internal discussions DPA held to gain a consensus on whether to collaborate with AF. The chapter will also examine efforts both parties took to secure successful passage of the amendment. It discusses efforts made by DPA and others to change public perception regarding discrimination through formation of the 'common ground coalition', a grouping of interested parties from all communities affected by the bill: disabled people, gay people, people with HIV/Aids. The chapter concludes with some comments about factors that made the lobbying efforts a success in this case.

In their authoritative legal text book on the New Zealand bill of rights, Andrew and Petra Butler, describe the passing of the disability clause within the Human Rights Act 1993 in these terms:

“When the disability clause was mooted for inclusion in New Zealand’s anti-discrimination laws, there was considerable debate about whether HIV/Aids

should be covered. In the end, sub para (vii) indicates that those who supported outlawing HIV/Aids discrimination prevailed”²⁰³

If the explanation of the legislative history of the Human Rights Act, with relation to the lobbying efforts needed to secure inclusion of the disability clause, was left as described by Butler & Butler there would be a substantial gap in knowledge as to the lobbying that occurred to secure “the disability clause”. The purpose of this chapter is to expand upon this, to tell the story of the lobbying effort by DPA to secure a disability clause, to compare a successful with a non-successful lobbying effort by the disability community, and then draw out factors that distinguish a successful campaign from a non-successful campaign. By doing this that gap in knowledge will hopefully be filled.

This chapter begins by examining the legislative history to the Human Rights Act; it demonstrates how DPA found itself in a position in 1992 where it was approached by then Minister of Justice Doug Graham who advocated for the non-inclusion of disability in the soon to be passed Human Rights Act. It was this piece of intervention by a Justice Minister which tipped the balance to start the lobbying by DPA and others in 1992.

Initially, however, an examination of the legislative history of human rights legislation in New Zealand is necessary to clarify both the state of the law and the role of individual state actors in the passage of the law which led to the interaction between Minister Graham and DPA in 1992.

The Genesis of the Human Rights Act 1993

²⁰³ Butler, A & Butler, P, *The New Zealand Bill of Rights Act: A Commentary* (Wellington, LexisNexis NZ Ltd, 2005) p. 17.8.14,488

The Human Rights Act 1993 was the end result of the amalgamation of two pieces of existing legislation, the Race Relations Act 1971 and the Human Rights Commission Act 1977. Both pieces of legislation built upon the grounds of illegal discrimination over time, as well as the remedies available. In addition, the penalties available for remedy were increased over time.

The Race Relations Act 1971

The Act is significant in that it was the first piece of legislation to make the treatment of people in a discriminatory manner illegal. The categories that the Act created for which discriminatory treatment justiciable were cast very narrow. The Act made race, ethnic or national origins grounds for unlawful discrimination, as well as discrimination directed toward any relative of a person to which unlawful discrimination is already a factor.²⁰⁴

Once the Act set up grounds in which illegal discrimination could be claimed, it went about setting out areas where illegal discrimination could be claimed. It was illegal to discriminate against a person in: access to public places, vehicles and facilities, the provision of goods and services, the provision of employment, housing accommodation and advertisements.²⁰⁵ The Act also created the crime of publishing or distributing material considered threatening, abusive or insulting, which it terms as 'Racial Disharmony.'²⁰⁶ The Act went further and made offences of 'intending to incite racial disharmony' through distributing material, or making statements that are intended to create ill will.

The Office of the Race Relations Conciliator was set up under the Act.²⁰⁷ Their role was to investigate any breach or potential breach of ss.3-7.²⁰⁸ The Office of the Race Relations

²⁰⁴ <http://legislation.knowledge-basket.co.nz/gpacts/reprint/text/1971/se/150se3.html> Accessed 7/4/12

²⁰⁵ *Ibid*

²⁰⁶ <http://legislation.knowledge-basket.co.nz/gpacts/reprint/text/1971/se/150se9A.html> Accessed 8/6/12

²⁰⁷ <http://legislation.knowledge-basket.co.nz/gpacts/reprint/text/1971/se/150se10.html> Accessed 8/6/12

²⁰⁸ The Race Relations Act 1971

s.3 access to public places,

s.4 vehicles and facilities; s.5 the provision of goods and services;

Conciliator had responsibility for investigating s.9A of the Act, the 'Racial Disharmony' provision. The Act was intended to bind the Crown²⁰⁹ but did not limit or affect other pieces of legislation, or have an overriding impact upon the whole of government.²¹⁰ It was not intended to change the way that government did business.

The Human Rights Commission Act 1977

The Human Rights Commission Act 1977 was a continuation of the legislative tradition begun by the 1971 Act. The 1977 Act expanded the 1971 Act in two important ways. First, the Act established the Human Rights Commission, and second, the Act broadened categories of illegal discrimination that were justiciable under Section II.

The Human Rights Commission's functions were to educate the public in respect of observance of human rights and invite and receive submissions from the public on matters affecting human rights. The Commission had a statutory obligation to report to the Prime Minister on progress made toward the repeal or elimination of provisions inconsistent with Part II of the Act.²¹¹ The 1977 Act gave the Commission the power to investigate any act or omission that 'is or appears to be in breach of a Part II. ²¹²

Part II lists the grounds of illegal discrimination: sex, marital status, or religious or ethical belief of that person. ²¹³ The Act lists the areas in which it is illegal to treat a person differently,

s.6 the provision of employment,
s.7 in the area of land, housing and other accommodation and advertisements

²⁰⁹Race Relations Act 1971 s.2

²¹⁰s.35 Race Relations Act 1971

²¹¹See Human Rights Commission Act 1977 ss 5(1) (a-e), 5(2)(a-c)

²¹² S.34(1) Human Rights Commission Act 1977

²¹³ The Human Rights Commission Act 1977_Part II Grounds of Illegal Discrimination

the areas are: an employment situation;²¹⁴ access in public places, vehicles, and facilities;²¹⁵ in the provision of goods and services;²¹⁶ to land, housing and other accommodation;²¹⁷ educational establishments;²¹⁸ discrimination by subterfuge;²¹⁹ and measures relating to childbirth.²²⁰

As the result of the 1987 election the Labour party had made a manifesto promise to review both the Human Rights Commission Act 1977 and the Race Relations Act 1971. In response, in 1990 the Human Rights Commission Amendment bill was introduced into Parliament. The purpose of the Bill was to review the grounds under which discrimination was deemed unlawful and to eliminate sexual harassment.²²¹ The grounds proposed under the 1990 Government Bill included: age; health status, (which included disability and disease), sexual orientation, pregnancy, political opinion, trade union involvement, employment status, beneficiary status, family status and the identity of a partner or relative.²²² The bill was unsuccessfully advanced due to a lack of support by the Justice Minister Bill Jeffries, who did not support the ground of 'health status', Charles Chauvel, who at the time worked as an advocate for the AF, (and who would go on to work within the office of Associate Health Minister Katherine O'Reagan during the 1990 National government) recalls that "an amendment"²²³ was put up in the 1990 bill that included a definition of sexual orientation.

²¹⁴S.15(1)

²¹⁵S.23(1)

²¹⁶S.24(1)

²¹⁷S.25(1)

²¹⁸S.26(1)

²¹⁹S.27(1)

²²⁰S.30(1)

²²¹ 16 Commw L. Bull. 1106-1990,1106

²²² *Ibid* at 1107

²²³ The 'health status' amendment which included sexual orientation and the separate ground of sexual orientation within the Human Rights Commission Amendment Bill 1990

Bill Jeffries, Minister of Justice, voted against the amendment, due to the inclusion of that definition.”²²⁴

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Chauvel expresses the opinion that conservative governments are “less likely to take human rights analysis, than are liberal ones.”²²⁵ The evidence would suggest less of a bright line between conservative and liberal Governments than Chauvel suggests.

The 1990 Bill did not proceed. Instead, the incoming National Government introduced a new Bill, the Human Rights Bill which would become the Human Rights Act 1993. Chauvel states “...the incoming Minister of Justice, Doug Graham, ordered a new revision of Human Rights Commission Act 1977”. It was Chauvel’s recollection of the new Minister of Justice, Graham’s position as expressed to both DPA and AF that, “his preference was for neither disability nor sexual orientation to be included within the new Act”.²²⁶

Two broad themes underpin the effort that the DPA and the AF made to include disability in the Human Rights Act. First, the DPA claim that successive governments have attempted to maintain rhetorical support for human rights standards, while as a matter of policy have moved away from that support due to political and ideological imperatives. Christie argues that:

“...governments have moved away from that support due cost cutting imperatives associated with ideological support for the rolling back of the state”.²²⁷

²²⁴ Pers comm. Charles Chauvel MP 9/2/12

²²⁵ Pers comm. Charles Chauvel MP 9/2/12

²²⁶ *Ibid*

²²⁷ Christie, Nigel (2009) “Access to Marriage for Same-Sex Couples in New Zealand: A Matter of Human Rights”

An alternative explanation highlights personal objections by Ministers of both Conservative and Liberal tendencies to unpalatable clauses within legislation hinting at a split between moral conservatism and amoral liberalism playing out in Parliament.²²⁸ This environment in which there was a lack of enthusiasm for new human rights protections on the part of all political parties provided the context in which DPA's campaign unfolded. Charles Chauvel explains, combining the fact that the National government was less likely to pass human rights legislation with the fact that Minister of Justice Graham had signalled his personal objection to passing the Human Rights Bill with protections for either people with disability or for people with HIV /Aids:

“.... the big unavoidable fact is that if the National government would have got its way, both disability and sexual orientation would have been excluded from the Act”

This statement threw both DPA and the AF together, connected by the discrimination they both faced and justice they were being possibly collectively denied.

Second, the interaction that DPA and people with disability they represent have traditionally had with politicians or officials was characterised by the response that politicians gave to DPA. Issues were framed as disability specific issues. DPA's Dave Henderson explains:

“An MP could deny that human rights belonged to people with disability but found it much harder to deny that they could belong to the larger group of disabled people and people with Aids and gay people.”²²⁹

²²⁸ Both Labour and National Ministers' of Justice have refused to endorse disability clauses due to the presence of sexual orientation and HIV clauses within the disability clauses of human rights legislation.

²²⁹ Pers comm. Dave Henderson 21 / 03 / 2012

This coloured the interaction on two levels. First, politicians and officials saw disability as a limited issue pertaining to just disabled people which could be traded off. Second, disabled people saw interacting with politicians and officials as a negative experience where they would have their concerns confined to technical matters relating to disability.

Henderson recalls the moment where both DPA and the AF decided that to join was the best option for both groups. Henderson recalls that moment as being a meeting in 1992 prior to the Human Rights Bill going before Parliament. Present at the meeting were representatives from DPA, the AF and Katherine O' Reagan. In Henderson's recollection he came away believing that "collectively we could achieve a win, collectively a greater strength than individually"²³⁰

By re-framing the issues both groups experienced as discrimination, both were able to have different conversation when lobbying to politicians. As both had experienced discrimination based upon who they were, both could effectively communicate that in their communications with Ministers and officials. Where DPA had not been able to transfer their message into lobbying success was due to their lack of personal connection with important Ministers, officials and their inability to effectively communicate their message through the media to the general public. The AF had better connections with politicians and officials. Henderson would meet weekly with the AF during the 1992 to 1993 period when the bill was in front of the house. A key part of discussions related to the numbers in the house for and against the bill and MPs that were marginal in terms of their voting. Henderson recalls talking to AF members about "who were approachable in Parliament."²³¹ In Henderson's opinion that was

²³⁰ *Ibid*

²³¹ Pers comm. Dave Henderson 21 / 03 / 2012

very valuable as it saved time, and he could focus time and energy upon the important meetings.

Despite the efforts of successive governments to limit liability to human rights instruments DPA began a lobbying effort after the 1992 meeting in Katherine O'Reagan's office to get disability added to the grounds of illegal discrimination granted protection under what would become s.21 of the Human Rights Act. DPA made submissions in conjunction with the AF that an expanded definition of disability be included into the Human Rights Bill. DPA in their general submission stated:

"However, the assembly, because it appreciates the difficulties people suffer when there is discrimination, regrets that the Bill does not make it illegal to discriminate against people on the basis of their sexual orientation, or on the basis of having organisms that cause disease, e.g. HIV." ²³²

DPA began the lobbying effort in full knowledge that the Minister of Justice had personally made statements stating his preference for the non-inclusion of both disability and sexual orientation within the Bill. When the Minister's preference was combined with the previous lack of success on the bill of rights campaign DPA was presented with a real challenge, at what was an important time in the organisation's history, after the successes of the 1981 Year of Disabled People and following the UN Decade on Disabled People. Perhaps it was the last opportunity DPA would have to secure legislative protection for the human rights of disabled people in New Zealand?

²³² Disabled Peoples Assembly (NZ) Submission #80 to the Clerk of the Committee, Justice and Law Reform Committee, 25th February 1993

An important initial question to answer relates to why DPA not just lobby for a disability specific clause within the Human Rights bill. To do so would, according to the comments by Hon. Dr Michael Cullen in the House²³³ ensure a legislative victory and appear to be the rational course of action to take from a legislative perspective. By joining up with the AF DPA appears to have made the legislative path more fraught and less secure. By going it alone DPA could secure a potential legislative victory.

Paul Curry, Manager of Disability Services within the Ministry of Health during the time of the passage of the Human Rights bill and key advisor to Katherine O'Reagan on disability issues relating to the bill sums up his understanding of the reasons for DPA joining with the AF as being centred upon 'Opportunity', based upon the legislative timetable and the two groups having a common agenda. The theme of common agenda in Curry's view was through:

"Members of the disability community viewing discrimination on the grounds of sexual orientation as the same issue as disability discrimination, and the more enlightened members of the disability community saw that as not dissimilar to having a disability either."²³⁴

Another explanation is needed than that of legislative opportunity for DPA and the AF working together. Chauvel worked for the AF in O'Reagan's office during the passage of the Human Rights Bill. Chauvel comments upon the strategy of the AF during the passage of the Bill:

"... the decision was made to try for a comprehensive definition of disability, the tactical reason for the decision was that it was thought there would be

²³³ See note 13

²³⁴ Pers comm. Paul Curry 15/2/12

strength in numbers, having missed out previously, it was felt there was nothing to lose by teaming up.”²³⁵

Chauvel further states that:

“... as a member of the AF Board I had personally seen discrimination directed toward people with Aids and homosexual people and didn’t like it ... at this point it was realised that it wasn’t about being the most popular or largest group, but if they didn’t pool their resources, everyone would miss out.”²³⁶

Commenting on the underlying strategy for the AF over whether to work with DPA, Chauvel suggests both communities saw the outcome of getting disability and sexual orientation put into the Act as being of such high importance, the collective view, at that moment was to work together: “... as when disability and sexual orientation were excluded from the Bill of Rights, and both groups thought that there was a chance that it could happen again, after the statement from the Justice Minister, it was a ‘we just have to get it in’ moment”²³⁷

In Chauvel’s mind the strength in numbers argument was more compelling. It was also being advanced by Anne Hawker from DPA when it decided to advocate for a broad definition of disability.

Hawker, DPA President at the time of the passage of the bill comments upon the strategy DPA employed:

“DPA made the decision not to advocate for ADA style legislation, for positive discrimination or affirmative action as DPA wanted an inclusive piece of

²³⁵ Pers comm. Charles Chauvel 9/2/12

²³⁶ Pers comm. Charles Chauvel MP 9/2/12

²³⁷ *Ibid*

legislation that included all people experiencing discrimination not a separate piece just for the disability community.”²³⁸

Henderson agreed with Hawker, not to pursue ADA style legislation for positive discrimination or affirmative action.²³⁹ This decision affirms Henderson’s commitment to human rights over narrower legislative protection for people with disabilities alone. For Henderson the thinking was that to pursue a narrow strategy would lead to an internal fight within the disability community over who was within the definition, who was ‘disabled’ for the purposes of the law and who was not. Members of the deaf community had already expressed at that time the preference not to be ‘lumped in’ with the disability community in preference to their description of themselves as a linguistic minority.²⁴⁰

The definition issue signalled much larger issues for DPA concerning disability identity and personal fears which would be debated at length internally within DPA over whether to join with the AF. Commenting upon the larger question for DPA of whether to work at all with the AF, Henderson recalls the protracted decision process:

“Within DPA there was discomfort against the grouping with the AF, but the reality was that when it was discussed at NEC level the majority decision was to proceed with the grouping with AF.”²⁴¹

Lobbying for change

Wendi Wicks, Wellington DPA, recalls the starting point for the lobbying from the disability community perspective in relation to the campaign was a petition from a DPA member in Whanganui, Kevin Whittaker in 1987. When challenged as to why there was no

²³⁸ Pers comm. Anne Hawker 28/3/12

²³⁹ Pers comm. Anne Hawker 28/3/12

²⁴⁰ Pers comm. Dave Henderson 21/3/12

²⁴¹ Pers comm. Dave Henderson 21/3/12

push by the disability movement for a large scale legislative effort prior to 1990, Henderson states:

“prior to 1990 DPA had been focussed upon achieving the goals of building up its regional networks which were becoming strong by the end of 1989, setting up and implementing Total Mobility from the funding that had come from Telethon as well as the Teletext service”.

Wicks states that the fact that the movement hadn’t pushed for legislation in the past created a backed-up desire to begin a campaign from the grass roots. Stemming from that desire, were: “so many complaints that we couldn’t make” and those “experiences of discrimination had bitten into people’s souls.”²⁴² This desire for recognition by anti-discrimination legislation was at the heart of the campaign to gain protection.

Legal and Illegal Discrimination

Before lobbying could start on the substantive issues relating to the inclusion of the disability clause DPA needed to focus its attention upon a piece of work it had been collaborating with the Human Rights Commission. The work related to a long-held exception to human rights legislation relating to disability. DPA would make a submission to the Select committee advocating against the exception.

Hawker saw that DPA would need to communicate with the Human Rights Commission with regard to potential pieces of work relating to exceptions to the Human Rights bill. One of the long standing exceptions to human rights legislation is insurance. DPA worked hard to counter fears being created by the Insurance council lobbying for a distinction to be included in Human

²⁴² Pers Comm Wendi Wicks 27/3/12

Rights legislation between legal and illegal discrimination. The Insurance lobby argued that for business purposes it needed to apply risk to categories of the population and do this through the use of statistical and actuarial risk tables. The insurance industry has successfully lobbied for this practice to be termed legal discrimination.²⁴³

At the heart of DPA's concerns were two fears: first, that the exceptions were based upon subjective opinion: and second, those exceptions based upon subjective opinion carry inherent prejudices about disability which are then institutionalised within the law.

The insurance and superannuation sectors have long maintained the right to discriminate based upon class of risk. The insurance sector determines the costing of policy holders based upon actuarial or statistical risk. On this basis different classes of people are classified as having higher or lower risk and a higher or lower price is attached to each class of person. In terms of the Human Rights Act such a process would be classified as a breach of s.44 'provision of goods and services' on less favourable terms by reason of any of the prohibited grounds in Part II.

DPA and other parties argued in submissions that the distinction between legal and illegal discrimination was arbitrary and placed disabled people in a discriminatory position. DPA argued that the inclusion of 'reputable medical opinion' clause allows for gaps in knowledge and treatment variation possibilities in different parts of the world. The inclusion of 'reputable medical opinion' and the fear by the disability community that the distinction between legal

²⁴³The LOA (Life Officers Association) lobbied both the Minister of Justice and Associate Minister of Health for the continued distinction between legal discrimination, based upon actuarial or statistical data and illegal discrimination based upon a ground within Section II of the Human Rights Act. DPA (Disabled Peoples Assembly NZ) lobbied that actuarial data is open to subjective opinion, therefore is discriminatory.

and illegal discrimination is arbitrary due to its being based upon actual data is supported by Ministry of Justice internal documents which suggest that:

“... it is impossible to assemble up to date data in sufficient reliable volumes in respect of every disability and every factor affecting that disability. Insurers must therefore rely upon medical and actuarial experience and opinion based upon familiarity with any available data and with the field of work.”²⁴⁴

Additionally, DPA argued that the inclusion of ‘reasonable to rely’ allowed insurance companies to price based upon commercial imperative, leading to pricing differentiation, which would be in and of itself discriminatory.²⁴⁵

In submissions to the select committee one specific concern was raised in relation to diagnoses and risk related to mental illness. The Mental Health Foundation raised the concern that the Insurance industry contradicts itself when stating that mental health is hard to define while also requiring that both mental and physical disabilities be treated the same.²⁴⁶

Another concern expressed by the Mental Health Foundation was the way that the Insurance Industry assesses both physical and mental disability as having similar risk profiles while at the same time stating that “mental illness cannot be measured in the same objective way as a physical disorder.”²⁴⁷

The Insurance industry receives an exception to s.44 which provides for it to discriminate in the context of insurance premiums. The exception is contained within s.48. DPA’s submission

²⁴⁴ Ministry of Justice LRD16-1-1-1 CP HRBLOA

²⁴⁵ DPA Submission on cl.62 to the Justice and Law Reform Select Committee 25 February 1993

²⁴⁶ O’Hagan, M “A fair deal?” Insurance for people with a diagnosis of mental illness in New Zealand: A discussion Paper for the Mental Health Foundation (Mental Health Foundation, September, 2009) p.11

²⁴⁷ *Ibid* at 12

was centred specifically upon the clause in s.48 (1) (a) (ii) which focusses on the concept that when no actuarial or statistical data is available, ‘reputable or medical advice’ shall be sought and relied upon when basing risk decisions. DPA’s argument was that this practice opened the possibility for subjective opinion to be accepted along with actuarial and statistical data. When allocating insurance premium risk, s.48 (a) (i) provides that:

s.48(1) (a) (ii):

Where no such data is available in respect of persons with a disability, *reputable medical* or actuarial advice or opinion, upon which it is *reasonable* to rely, whether or not contained in an underwriting manual;²⁴⁸

In response the ISI (Investment Savings & Insurance Association)²⁴⁹ argued that it has always been common practice within the industry to rely upon a “combination of data and advice or opinion, rather than relying solely upon one or the other”.²⁵⁰ It is unlikely that one will provide a perfect match and that the combination of both data and opinion from both internal and external experts will be sought in order to reach a robust assessment.²⁵¹

DPA through their written and oral submissions attempted to influence the Select committee to vote against the exception in s.48. However, the exceptions based upon data and opinion were included. At this point DPA was defeated upon a narrow technical issue by a powerful industry lobby, this initial defeat only adds strength to the argument that people with disability need legislative protection from the broader discrimination.

²⁴⁸Human Rights Act s.48 (1) (a) (ii)

²⁴⁹ <http://www.isi.org.nz/> Accessed 17 / 5/ 12

²⁵⁰Investment Savings & Insurance Association of New Zealand “Submission to the Human Rights Commission on the Discussion Paper: Review of the Guidelines on Insurance and the Human Rights Act 1993” (ISI, December, 2006)p.4

²⁵¹ *Ibid* at 4

Within DPA

By 1992, after the meeting with the DPA, and the AF in Katherine O'Reagan's office, it was clear that all parties would mount a collective campaign. Several factors were in the minds of key people within DPA both Henderson and Hawker. First, both had lived through the unsuccessful bill of rights lobbying campaign in 1990. Second, both parties knew that the incumbent Minister didn't want disability included into the newly tabled bill. Third, the bill had just been defeated under the previous Labour Government due to lack of Ministerial support for the inclusion of 'health status' which included disability as well as sexual orientation. Fourth, DPA was buying itself a big fight to lobby for the inclusion of disability sexual orientation and HIV by collaborating with the AF in a fight against a Minister that was publically against all the above when as an organisation it had a legislative record that did not indicate it could deliver upon such a large agenda.

Within DPA there were, what Henderson describes as, "big arguments" over the best strategy to pursue. Henderson recalls that long-time DPA strategist and lawyer Quentin Angus was concerned over the possibility that Parliament would buy the disability argument but not the Aids argument.²⁵² Hawker characterised that time period as one of "robust debate" which she had to facilitate.²⁵³ Essentially the conflict within DPA boiled down to a debate between two sides. One side represented by lawyer Quentin Angus who felt that to partner with the AF represented a political risk, one which he personally was uncomfortable with. The other side was represented by Henderson who felt that DPA needed to advocate for a broad human

²⁵²Pers comm. Dave Henderson 21/3/12

²⁵³ Pers comm. Anne Hawker 28/3/12

rights position which included discrimination legislation which protects all people facing discrimination.

Hawker notes that personal opinion from members of DPA on the gay / lesbian issue at-times did cloud the debate within DPA, but comments that it was her role to ensure that everyone within DPA stayed on the issue and principle.²⁵⁴

Henderson and Hawker moved DPA to a position of unity and to focus upon broader human rights goals. Hawker saw her as role to unify the Executive around one position and to remind the executive that they had to stick to their principles.²⁵⁵ This decision by Hawker to ‘stay the course’, around fundamental values while seeking unity created the possibility for internal disunity while the organisation decided exactly what the best course of action was. Henderson came to the DPA with a commitment to broad human rights principles. Henderson’s motivation was to address the amount of discrimination in New Zealand, as a result Henderson was comfortable collaborating with groups like the AF in order to achieve a broader human rights goal. As chief executive he was in a position to “win over” internal arguments when a decision was needed upon strategy before talking a policy / strategy decision to the NEC.²⁵⁶

Both Hawker and Henderson combined to unite the DPA at a time of potential fracture over a major issue that could have split the organisation. Together they worked to bring the disparate factions within the disability community represented upon the NEC together to

²⁵⁴ *ibid*

²⁵⁵ *ibid*

²⁵⁶ See note 54

agree upon the issue of advocating for a disability clause to be included within the Human Rights Act.

Much more work was needed to secure legislative victory. In the 1990 campaign DPA had relied upon Angus in combination with Henderson representing DPA to select committees on matters relating to the law. Angus argued in a clear and concise manner points that non-lawyers could not. In this campaign; different skills would be needed: skills that DPA did not have; skills that in Henderson's mind DPA would have to collaborate with others to acquire.

Within Parliament

In 1993 Paul Curry was seconded from the Ministry of Health to the office of the Associate Minister of Health, Katherine O'Reagan. Curry was the Manager of Disability Support Services and in addition a foundation member of DPA. Curry had a history of disability activism which he turned into a career of public service.

Curry describing his early activism:

"... we had marches on Parliament, petitions drawn up about our human rights were handed to the Prince of Wales when he visited, a whole march from Lower Hutt to Wellington, a whole bunch of activists chained ourselves to the rails on the stairs of Parliament."

Later, describing his role as a public servant:

"My job here is to make sure that it gets back the right way to help the constituency, I'm here to serve."

Part of Curry's role of service during the passage of the Human Rights bill was to support the Associate Minister whose role was "trying to convince others, colleagues, [Curry expresses] that it's always the way, that a passionate Minister understood that the legislation could make a difference for people with disabilities and for those with regard to sexual orientation."²⁵⁷ Stating that his role was to write cabinet papers, briefing notes for the Minister to convince her colleagues that they should support the bill. He states that there was about an equal amount in favour as opposed, but in his opinion, "it's not a big vote catcher".²⁵⁸ Curry says that "it was fascinating to be able to push a human rights issue in a political sense when certain ideologies were more concerned over whether this was going to lose votes"²⁵⁹. When Curry refers to 'certain ideologies' he is referring to the dominant ideological strain of economic liberalism' present within the National party at the time of the passage of the bill.

Associate Minister of Health O'Reagan introduced the Supplementary Order Paper (SoP 243) to include disability within the Human Rights Bill. The definition of disability included the term 'organisms within the body causing disease', the legal definition for HIV/Aids as well as sexual orientation as a separate ground of illegal discrimination. O'Reagan was forced to introduce the measure as a Private Member because of the Minister of Justice Doug Graham's earlier opposition.

AF lawyer Chauvel, who was drafted into the Associate Minister's office to provide advice on the Bill notes that "most of Labour were on side, although not all of them. There were difficulties with National members Doug Graham, John Banks, Bill Birch, with support coming

²⁵⁷ Pers comm. Paul Curry 15/2/12

²⁵⁸ *ibid*

²⁵⁹ See note 32

from Jenny Shipley, Ruth Richardson, the women's wing and the urban liberal wing of the National Party".²⁶⁰

The political risk of collaboration

During the third reading in the House of the Human Rights Bill on the 27th July 1993 the Hon. Dr Hon. Dr Michael Cullen commented that "it had been a long hard struggle to get that particular part of the Bill through" [referring to the provision on disability]. Dr Cullen went on to say it had been a long struggle because, quite properly, the matter had become bound up with the issue of sexual orientation ... In Cullen's view:

"... if we could have separated the issue of disabilities it could have been dealt with quickly".²⁶¹

The reason for the negative reaction from the House to the HIV/Aids issue can be traced back to the passage of the Homosexual Law Reform Act 1986. Chauvel comments:

"... the Labour caucus from 1987 had been scarred by the passage of the Homosexual Law Reform Bill and didn't want to go through another one of those the attitudes of the conservative members of the caucus had hardened as a result."²⁶²

The debate within the House over the Homosexual Law Reform Bill was polarising, bringing out sharp divides based upon personal preferences between members due to the fact that the Bill was voted upon as a conscious matter.

This debate extended into the reading of the Human Rights bill with opponents such as Geoff Braybrook, [Labour, Napier], opposing it on the grounds of the "likely influences on youngsters ... and not liking the thought that in the future something amounting to 'the

²⁶⁰Pers comm. Charles Chauvel MP 9/2/12

²⁶¹Human Rights Bill 27 July 1993, (Hansard, 16973)

²⁶² Pers Comm. Charles Chauvel 9/2/12

thought police' could say what is or is not correct."²⁶³ The Minister for Internal Affairs, Graham Lee [National, Coromandel] expressed opposition on the grounds that "the family unit has been challenged today ... I want, and I hope that any other parliamentarian would want, this country to be one that we all regard as one of decency and right standards."²⁶⁴

Facing opposition the collaboration between DPA and the AF to collectively lobby for expansion of the disability clause within the Human Rights bill to include 'organisms within the body capable of causing disease' or HIV/Aids, was itself unstable. Internally DPA, more specifically Angus was concerned that to work with the AF attracted some degree of political risk. Angus' concern, as recalled by Henderson, was that negative public opinion directed toward the AF, relating to the HIV / Aids issue could have an impact upon the DPA, and could potentially damage the success of the amendment. Actual statistical data and surveys indicated that support for the Homosexual Law Reform Bill had no negative impact upon MP's at the time. Association with, and support for the bill was seen as a positive attribute for MP and potential MPs.²⁶⁵ In addition to the statistics that refute Angus' concern openly gay DPA members by their very membership in DPA demonstrate that they were experiencing two forms of discrimination and were just as deserving of protection.

Henderson speaks of the value that collaboration would bring to DPA. As far as he was concerned, working with the AF brought DPA a skill set that DPA didn't possess at that time: "DPA was more likely to succeed if we [DPA] tied ourselves to the skill set of the AF"²⁶⁶. The

²⁶³ Human Rights Bill 27 July 1993, (Hansard, 16935)

²⁶⁴ *Ibid* at 16968

²⁶⁵ "AIDS AND HUMAN RIGHTS "The Importance of adding 'sexual orientation' and 'disability' to the Human Rights Commission Act (New Zealand AF 1990) p. 11 (11.1)

²⁶⁶ Pers comm. Dave Henderson 21/3/12

skill's he refers to were the national structure of the foundation combined with connections to MPs. It was, "a package that could not be denied"²⁶⁷ In Henderson's understanding the AF brought to the DPA an ability to gain access primarily to the key MPs, but in addition institutional knowledge from legislative campaigns regarding who are good MPs to contact, who are 'good people' in the public service to talk with. However, the skill set that the AF brought that was of most value to DPA was their ability to relate to MP's on an inter-personal level, to build relationships, soft skills that DPA was lacking. DPA's relationship with the media has historically been a strained one, due to the way the disability community views the way the media portrays people with disability, Henderson explains:

"In 1981 the media got all excited, presenting lots of stories, but there were lots of holes in terms of the language of how disability was presented, suffering was were the media used language out of ignorance to present disability."²⁶⁸

Here Henderson demonstrates how the media use language in a manner that portrays people with disability in a negative light as 'suffering' or afflicted with disability, this impacts upon how the public views people with disability. He continues:

"Now, the language is better, due to Robyn Hunt, and education efforts but the language was 'crude' in 1981"²⁶⁹

The use of such language had historically alienated the leadership of DPA from the media who all grew up experiencing such treatment during the time of IYDP. The adoption of a 'siege

²⁶⁷Pers comm. Dave Henderson 21/3/12

²⁶⁸ *Ibid*

²⁶⁹ *Ibid*

mentality' by DPA when dealing with the media had resulted in a negative relationship which in turn resulted in disabled people being portrayed negatively to the public.

When both DPA and the AF met with MPs to argue for inclusion of the disability clause, Henderson says that AF lobbyists brought contacts that enabled both to secure meetings with MP's that DPA just could not get as an organisation by itself. When or if DPA was meeting with an MP or an official by itself, an issue would be argued narrowly as it affected solely the disability community, or a disabled person. By collaborating with a larger, better resourced group, on access and argument, both DPA and AF made it much harder to deny the strength of the collective argument. In Henderson's words "It becomes an unassailable argument at that point, to make an argument that MPs could not argue against."²⁷⁰

The concern Angus expressed during internal DPA meetings over whether to join forces with AF appears to have been misplaced. Not only was the fear not supported by statistical data,²⁷¹ concerns over whether collaboration with the AF would have a negative impact were dispelled by Henderson himself who outlined the positive benefits to working together.

The way that the disability community is portrayed in the media and seen by the public has long been a concern within the disability community. In order to gain public support for the legislative campaign and explain to the public the importance of the campaign, the Common Ground Coalition was formed.

²⁷⁰*Ibid* see note 48

²⁷¹ See note 264

Common ground coalition

Mike Gourley is a former president of the Disabled Persons Assembly.²⁷² Gourley's commitment to the disability community is long standing, participating within the community as a researcher, activist and role model. Gourley has had a career in many public-sector organisations as well as within the disability sector. A feature of his work for and with the disability community is a long-standing commitment that disabled people would be able to live the lives they want to live in equality with the non-disabled community. Gourley has fronted Radio New Zealand's long-standing disability issues programme.²⁷³

Gourley's proudest moment was to be a part of the 'Common Ground' coalition. Common Ground was an initiative on the part of the disability community bringing together anyone that had 'common ground' in terms of facing discrimination.

Common Ground was launched at the National Library in Wellington in 1993. The purpose was to bring together groups that had a collective desire to achieve social change through the passage of the Human Rights Act amendment on disability and sexual orientation.

The purpose of Common Ground was to run a campaign whose purpose was to impact the way the public viewed and responded to discrimination. The campaign was grounded in the concept of common ground indicating that it was not disability-focussed or gay / lesbian focussed but discrimination-focussed.

Common Ground involved getting different members of disability community together as well as members of the supporting communities such as the Gay/lesbian, HIV/Aids communities for the bill. As time went by, organising the launch Gourley commented that "the two communities, Gay/lesbian, HIV and disability built a definite solidarity."²⁷⁴ Meetings were

²⁷² Gourley was DPA President from November 2003 and November 2008

²⁷³ 'One in Five' see <http://www.radionz.co.nz/national/programmes/oneinfive> accessed 7/5/12

²⁷⁴ *Ibid*

held to organise the launch in disability community members' places of work, with the coalition using communication tools such as press releases, the launch itself and face to face communication.

The coalition used networks both within and outside of government to spread the messages of human rights, equality and equality of opportunity for all. When asked what the thinking was that led to the creation of Common ground Gourley comments "... if the public became more aware of the issues they would put more pressure on the politicians."²⁷⁵

Gourley comments':

"... it was more likely that we would be included if we got the public supporting us as well ... there was definitely a unity in numbers."²⁷⁶

Common Ground is significant for several reasons: First, it signifies disabled people taking control of the way that they are perceived by the general public, thereby empowering themselves. Second, it signified disabled people's groups working with other groups, collaborating on broader issues, such as discrimination that affected more than just disabled people. Third, by collaborating with affected parties in a 'common ground coalition' disabled people's groups no longer could be marginalised as an outsider group but represent more mainstream concerns and normalise their membership to the general public.

The campaign to include a disability amendment provision in the SoP (Supplementary Order Paper 238) included two amendments. First, that 'presence in the body of organisms capable of causing illness' should be included within the definition of disability, and second, a separate

²⁷⁵ *Ibid*

²⁷⁶ Pers comm. Mike Gourley 4/5/ 12

clause should be established including 'sexual orientation', which includes: heterosexual, homosexual, lesbian, or bisexual orientation.

The SoP containing the disability and sexual orientation provisions was successfully passed after an amendment to that SoP was introduced by Graham Lee. That amendment was defeated Ayes 15, Noes 58.²⁷⁷

The second amendment to include sexual orientation, was successfully passed Ayes 48 Noes 26.²⁷⁸

The Human Rights bill went to a final reading where it was passed into law.

What factors lead to a successful campaign?

Several factors contributed to the success of the DPA effort to include disability as a ground of illegal discrimination within the Human Rights Act 1993. First, the framing of the debate as one of a broader human rights concern, rather than a disability-specific clause or a gay rights clause which established the need for the clause and the basis for both DPA and AF's approach. Second, the presence of policy advocates both within and outside of Parliament, combining with skilled advocates within the disability and Aids community.

Third, the mere process of building coalitions between the disability community and the Aids community around issues of obvious shared interest would prove crucial.

And finally, mobilisation of the grass roots of the disability movement to support the campaign was instrumental. It was important for DPA to interweave the discrimination narrative into the campaign, introducing the experiences of disabled people, communicate real experiences that have actually happened to disabled people, and have been left without redress. This forms the heart of the campaign.

²⁷⁷ Hansard Human Rights Bill, 27 July 1993, 16954

²⁷⁸ Hansard Human Rights Bill, 27 July 1993, 16955

Henderson and the whole leadership within DPA made the decision to lobby for the inclusion of a broad disability clause. Henderson summaries DPA's strategy to lobbying in collaboration with the AF, the focus was to:

“... pass legislation requiring a ‘broad church’ of groups in favour of the legislation.”²⁷⁹

Henderson, joined DPA with the “goal of addressing the amount of discrimination on New Zealand, so was comfortable with working with the AF.”²⁸⁰

Both DPA and the AF had members working within Parliament prior to the introduction of the Human Rights Act. Paul Curry, was a member of DPA during the time of the passage of the Act, and was manager of Disability Support Services, within the Ministry of Health. He was seconded to Associate Minister of Health, O'Reagan's office. Also seconded at the office was Charles Chauvel, who was on the board of the AF.

Chauvel notes that there:

“.... was always a commitment from the AF side of the issue to add both sides of the issue.”

With reference to the suggestion that there was not a unified strategy between the groups Chauvel suggests:

“There was never any suggestion that if we can't get sexual orientation, we don't need to worry about disability, or vice versa, everybody was clear that it had to be both ... some good lobbyists and strategists coming out of both

²⁷⁹ Pers comm. Dave Henderson 21/3/12

²⁸⁰ *Ibid*

strands [disability and sexual orientation] who probably made the difference of getting those two grounds in ...".²⁸¹

Curry echoes Chauvel's view, that there was a unified strategy with parliament:

"... from the disability perspective there was a belief that the issues were connected, that HIV/Aids could be a health-related disability and we all believed that if we pushed it together it was fine ... I [Curry] can't remember any debate saying we should just push it through for people with disabilities and take a different timeline."²⁸²

The fact that DPA was working with the AF caused, in the words of Wendi Wicks "a certain level of disagreement". Wicks suggested there was a range of opinions, and not everyone was united, not everyone was comfortable with gays and lesbians: ... "there were conservative opinions." For Wicks "the issue boiled down to an issue of inclusion within the Act, rather than temporary bedfellows" ... "we weren't entitled to make moral judgements."²⁸³ Hawker, views the time of disagreement within DPA as one that she personally had to "make sure that people's personal opinions on gay / lesbian did not cloud the issues before DPA, and remind DPA of the direction of the agenda."

For Gourley the fact that DPA was working with another group but still taking a leadership role on the issue of disability, was crucial. Gourley comments that his proudest moment of the campaign was the fact "that DPA had got in behind other groups where there was initial prejudice and were seen to be leaders on an issue."²⁸⁴

²⁸¹Pers comm. Charles Chauvel MP 9/2/12

²⁸²Pers comm. Paul Curry 15/2/12

²⁸³ Pers comm. Wendi Wicks 27/3/12

²⁸⁴Pers comm. Mike Gourley 4 /5 /12

When DPA lobbied for the inclusion of the disability clause and the inclusion of sexual orientation as a separate ground of illegal discrimination they chose a much harder lobbying battle. This decision came down to an internal split within the organisation between DPA lawyer Quentin Angus, mindful that the political cost of collaborating with the AF could spell the end of the disability amendment and CEO Henderson who supported a broader human rights position based where DPA as an organisation was collaborating with another organisation representing people facing discrimination based upon sexual preference.

The reason DPA chose the arguably harder lobbying path was to signal that disabled people collectively face the same issues of discrimination and prejudice as members of the able-bodied community and by working together with a group from the community that shares similar concerns, but also shares similar experiences of discrimination, the leadership within DPA felt that the decision could create a much stronger set of protections for all people.

Chapter 7 Conclusions

DPA had two very different lobbying experiences in the campaigns to include disability in the Bill of Rights Act 1990 and the Human Rights Act 1993. The organisation experienced the power of institutional players, people who have the power to either energise a campaign or to place its very existence in jeopardy. DPA would work with some of the most enthusiastic lobbyists to get disability included in the Human Rights Act and it would experience the support of the public through a media campaign associated with that lobbying campaign.

During the 1990 campaign the DPA encountered an institutional player in the form of Sir Geoffrey Palmer who was too great an obstacle for the organisation to overcome. He was an 'immoveable object' that effectively shut the campaign down. In 1993 DPA again found itself facing a potentially immoveable object in the form of Justice Minister Graham. Graham had stated that he did not want disability included within the Bill. In 1990 this would have stopped DPA in its tracks as it did with Palmer's insistence that disability be not included. The campaign in 1993 would be different. Several factors, outlined below allowed the 1993 campaign to be different and therefore successful. These factors included: the collaboration of the DPA with the AF; the way in which disability issues were framed; and the lessons taken from the unsuccessful bill of rights experience that would lead the DPA to a successful Human Rights bill campaign in 1993.

These conclusions have been drawn as a result of the process of interviews conducted with members of the disability activist community, AF lobbyists, members of the bureaucracy

working closely with the bills in Parliament and state actors influential to the bill's passage. Their input has allowed wider analysis to be made regarding the context in which both bills were passed. The conclusions are divided into three underlying themes, which resonate within both attempts made by DPA to influence the legislative process. The conclusions will be instructive for the NGO sector in the future when lobbying for legislative change.

With these general conditions in mind, there are three themes that characterise the differences in the lobbying between the 1990 campaign and the 1993 campaign. First, the collaboration of the AF with DPA around an 'issue of importance'. Second the 'reframing' of the disability issue as a human rights issue. Third, path dependence, when DPA was faced with the possibility of an unsuccessful 1993 campaign, mindful of their collective failure in 1990. This provided the extra-motivation to achieve a successful outcome.

Collaboration: the benefits of working together

Henderson knew the value that working with the AF brought to DPA. In Henderson's words, the AF brought DPA a skill set that DPA didn't possess, "PA was more likely to succeed if we, [DPA] tied ourselves to the skill set of the AF."²⁸⁵ The AF had a national structure, combined with connections to MP's. It was, "a package that could not be denied."²⁸⁶

For Henderson, it was as simple as recognising that there was real gain to be achieved from collaboration. The skills missing from the DPA included: access to skilled lawyers and lobbyists, who in turn provided the access to Ministers and officials that DPA had not had previously had access to. The AF also had positive relationships with the media. By working with the AF DPA could learn how to build relationships with the media, and with government

²⁸⁵ Pers comm. Dave Henderson 21/3/12

²⁸⁶ Pers comm. Dave Henderson 21/3/12

to achieve change. These were skills that DPA did not possess. In Henderson's experience when he and others from DPA wished to meet ministers on issues relating to disability, those meetings had been shifted down to an official's level. In Henderson's recollection when advocating for disability-specific issues on legislation, Ministers and officials would easily dismiss the lobbying as being a "disability issue". Where Henderson saw real value in working with AF was that by combining, the two organisations could not be dismissed so easily. Together the two brought power in numbers as opposed to a single issue brought by one organisation.²⁸⁷

Commenting upon why the DPA saw working together with the AF as being of high priority, Hawker suggests:

"DPA made the decision not to advocate for an ADA style legislation, (for positive discrimination or affirmative action) as DPA wanted an inclusive piece of legislation that included all people experiencing discrimination not a separate piece just for the disability community."²⁸⁸

DPA historically did not have good government relations, or good media relations, tending to see itself as a group, representing people marginalised from society and from the inner workings of government. In Henderson's mind the AF brought an ability to create good relations with government, the media and therefore the public. These were skills that DPA did not possess at that time.²⁸⁹

Issue Framing: A broad human rights or narrow disability issue

²⁸⁷ Pers comm. Dave Henderson 21/3/12

²⁸⁸ Pers comm. Anne Hawker 28/3/12

²⁸⁹ Pers comm. Dave Henderson 21/3/12

Both groups had experienced discrimination. But by re-framing the issues when meeting Ministers and officials both were able to broaden out their appeal when presenting to politicians. The reason the DPA had not been able to transfer their message into lobbying success was due to their lack of personal connection with important Ministers, officials and their inability to effectively communicate their message through the media to the general public. Both groups had experienced discrimination, based upon who they were.

After active discussion within the DPA there was support for legislation, an “inclusive piece of legislation that included all people experiencing discrimination.”²⁹⁰ Henderson supported the decision to pursue a broad human rights strategy over narrower legislative protection for people with disability. In his view to pursue a narrow strategy would lead to an internal fight within the disability movement as to who was within a disability definition, or who was ‘disabled’ for the purposes of the law and who was not. Internally, within the disability community, differences of opinion were expressed, none more so than that by Henderson when describing the decision by the D(d)eaaf community not to be “lumped in” with others within the disability community in preference to the communities’ self-description as a ‘linguistic minority’.²⁹¹

Path dependence: ‘we just have to get them in moment’

The DPA encountered opposition during the 1990 campaign from Sir Geoffrey Palmer when it lobbied to include disability within the bills freedom from discrimination section. Henderson recalls the position Palmer regarding the insertion of disability protections into

²⁹⁰ *Ibid*

²⁹¹ Pers comm. Dave Henderson 21/3/12 The deaf community has since rejoined the ‘disability’ community

the Bill of Rights being that “he didn’t buy it.” Palmer had a particular vision for the Bill, which was to restrain the power of the state. To include protections for disability would place an onus upon the state to take actions, especially in employment, housing and accessibility. For Palmer this went against the purpose of the bill therefore he rejected the lobbying by DPA outright.

This experience was to set up what was to be the most successful lobbying experience that DPA has had in its history. In 1992 the Human Rights bill went before parliament, again the Minister of Justice, in this instance Graham, who stated that he was personally against the insertion of disability as a ground of illegal discrimination. Chauvel describes the thinking behind the decision of the AF and DPA to work together:

“the collective view, at that moment was to work together ... as when disability and sexual orientation were excluded from the Bill of Rights, and both groups thought that there was a chance that it could happen again, after the statement from the Justice Minister, it was a ‘we just have to get them in’ moment.”²⁹²

“... at this point it was realised that it wasn’t about being the most popular or the largest group ... if we didn’t pool resources, everyone would miss out.”²⁹³

Chauvel’s comments are instructive; the lobbying for the inclusion of the disability clause was about securing basic human rights. It was a moment when being popular, or being the largest group, did not matter, it was about securing a minimum standard of rights for people with disability and people with HIV/Aids.

²⁹² *Ibid*

²⁹³ Pers comm. Charles Chauvel MP 9/2/12

DPA had come a long way from its creation in 1983, as an organisation with radical roots, protesting in the 1980s. The organisation then was on the outside of political influence. Crowther argues provocatively:

“why are organisations led by disabled people going to be better ... than organisations led by disabled people in partnership with other people?”²⁹⁴

This was the challenge that DPA faced in the 1990 legislative campaign, Crowther notes:

“... looking outward ... engaging and helping to develop new coalitions forged around the shared interests of people, who nonetheless have multiple and fluid identities and motivations, nevertheless wish to achieve the same goals and outcomes.”

Success for DPA came when the organisation combined with another organisation, the AF, something that arguably could be seen as less than a rational choice. The choice to partner with the AF empowered DPA as people and led to future positive outcomes for the organisation as a key player recalls it:

“After the Human Rights Act, [we] got a better hearing on issues such as the Building amendments, we still didn’t get everything we wanted but we got a better hearing because Katherine (Minister of Consumer Affairs) had enabled a new paradigm of lobbying to Parliament from grassroots which in the early nineties was pretty radical.”²⁹⁵

While the decision to partner with the AF presented risk for the DPA, it is also represented a high tide for the organisation, and one of the greatest achievements for the organisation.

²⁹⁴ Crowther, N (2007) “Nothing without us or nothing about us?” Disability & Society Vol.22 No.7 p.792

²⁹⁵ Pers comm. Dave Henderson 21/3/12

Mike Gourley sums up the feeling within the organisation regarding the Common Ground coalition which initiated the Human Rights disability amendment campaign:

“... the proudest moment in his career was to be a part of the ‘Common Ground’ coalition. Common Ground was an initiative on the part of the disability community bringing together anyone that had ‘common ground’ in terms of facing discrimination.”²⁹⁶

²⁹⁶ Pers comm. Mike Gourley 4/5/12

Appendix One

Interview Material

Interview with Charles Chauvel Conducted at Parliament Offices 9/02/2012

CC: My involvement with this began in 1986 when the HLRB was in the House, Part II of the Bill would have amended the then HRC Act to add sexual orientation to the HRC Act, that measure failed, although the decriminalisation measure in Part I was successful, it seemed obvious to me that a comprehensive anti-discrimination statute was desirable, both as a gay man and as a person who thinks that HR are important.

CC became involved with the AF and the Aids movement, became aware that there was a 'wider interest' than just prohibiting discrimination on the ground of sexual orientation, needed a protection for people that faced terrible ignorance and barriers that they faced

CC became in touch with wider groups / networks including DPA chiefly relating to health related discrimination including disability discrimination

A: Recognition on all of our parts that the issues were interlinked and if we joined forces we might have a better chance of prevailing than if we all fought separate battles

1989 amendment to HRC Act was put up that included a def. that included sexual orientation, Bill Jeffries, Minister of Health, voted against the amendment, due to the amendment

With election of 1990 National Govt, renew effort to get a comprehensive anti-discrimination legislation

CC had exposure to discrimination on the basis of health status as member of AF Board and “didn’t like it” DPA AF, a number of other organisation set up a group called “Common Ground” launched at National Library,

Doug Graham ordered revision of HRC Act, concluded that either disability and sexual orientation were not to be included within the new Act

At this point it was realised that it wasn’t a question of not being a less popular or larger group, but if they didn’t pool their resources, everyone would miss out.

Had been concerned when disability / sexual orientation were excluded from the BORA in 1990 and now there was a chance that they would be excluded again from the HRA, CC said they felt that it was a “we just have to get them it” moment

CC: expressed the view that disability was the more “frightening” ground than sexual orientation, at least they knew what GLB meant, transgender was left out, there were all sorts of arguments mounted against inserting disability into the Act, partly because of the wide definition insisted upon, which included organisms within the body.

Decision was made to try for a comprehensive definition of disability, tactical reason for the decision was that it was thought there would be strength in numbers, having missed out previously, and it was felt there was nothing to lose by teaming up

KoR persuaded to move SOP, as Minister of Health, most of Labour people were on side, although not all of them, difficulties with the conservative National members, Doug Graham, John Banks, Bill Birch, Support from Jenny Shipley, Ruth Richardson, women wing / urban liberal wing of the National party.

Majority on the SOP which got both grounds included into the HRB

CC always a commitment from AF side of the issue to add both grounds to the HRB, never any suggestion that if we can get sexual orientation we don't need to worry about disability or vice-versa, because of the Aids angle, everybody was clear that it had to be both.

There were some good lobbyist and strategists coming out of both of those strands who probably made the difference in terms of getting those two grounds in.

Q: interplay between Conservative Government an passage of Human Rights legislation

CC partly about timing, the National Government were in power when the HRA was passed, but the big unavoidable fact is that if the National Government would have got it's way both disability and sexual orientation would have been excluded from the Act

It took the courage of a brave MP who had reached the end of her political lifespan,
Minister outside Cabinet, deciding to do the right thing,

1987 Labour Caucus “scarred” by the HLR process, didn’t want to go through another one of
those, the attitude of the conservative in the caucus had been hardened by the experience,

CC: wrong to say that Labour should have done this in the 1980’S and failed, this was
National legislation, but it has gaps, the law was passed by National with the help of Labour
to get to a majority.

CC Conservative Governments are less inclined / willing to take a HR analysis, where as
social democratic governments tend to be more naturally inclined to do so, CC claims that
much greater progress was made under the Clarke Government on the issues of disability
and sexual orientation, than the end of that Government in 2008.

Q: A personal connection to the issue in relation to the passing of legislation

CC: During the passage of the Disability (UNCPDP) Act 2008 some of the National party
speeches toward the end were in the old mode of welfare model vs. the HR model, the
speakers were very sincere in the speeches, CC spoke to them afterwards and they had no
idea they were being patronising, very good evidence of a disconnection to the disability
issue as most of the speakers had probably never actually sat down and talked to a person
with a disability about their perspective on what a difference the Convention would make to
the lives of disabled people

If you know someone or have worked with someone with a disability then you will have a different perspective on it, and will be more inclined to want to make a difference on it in a positive way as opposed to an academic issue

Q; Comment made by Dr Michael Cullen, “Bill would pass with little difficulty if it was just disability”

CC: Struck at the time by the amount of uniformed comment at the time around adding HIV to disability especially from the medical community, a medical officer in Canterbury was concerned that it so would affect the blood supply,

Not aware that any suggestion that any of the groups were considering bolting from the strength in numbers position, no group “shopping” for better deals but CC has no knowledge if it did or did not occur

Interview with Paul Curry CEO Families Commission, conducted at Families Commission

15/02/2012

Q: Referring to Dr Cullen's comments in the 3rd reading of the HRB if it was just about disability, then the Bill would go through with very little opposition:

PC: I think the fact that the disability clause was present helped the HIV / sexual orientation get across the line, to have voted the HIV / sexual orientation clause out would have taken it all out

Q: Why did the Disability community join up with the Aids community at a time when the Aids issue was such a hot button issue?

PC: Opportunity really, it's not often that you can get legislation onto the legislation timetable, KoR associate Minister of Disability Issues, PC worked in KoR office, was responsible for drafting the legislation relating to disability, drafting Parliamentary questions relating to the Bill,

Members of the disability community say discrimination on the grounds of sexual orientation as the same issue as discrimination as disability discrimination, and then when you got to AIDS, the more enlightened members of the disability community saw that as not dissimilar to having a disability either

Q: Was it a broader HR concern?

PC: I think so, yes I really do think so, and there were some pretty enlightened people around in those days, Russell Kerse's Quentin Angus,

From a disability perspective there was a belief that the issues were connected, that HIV/Aids could be a disability and that we believed that if we put the whole together it was fine

I can't remember any debate saying we should just push it through just for people with disabilities and take a different timeline, we were deeply concerned that the homophobic lobby would derail our clause [the disability clause] going through, there was a concern about that, no doubt about it, but at the same time the coupling within the legislative timeframe was just fine to

Q: Why join with a lobby [GLBTG] who could potentially derail the disability clause?

PC: Opportunistic, the legislation was going to go before the house, KoR was interested in looking at all the issues that were missing from the legislation, and we all agreed that it should go up as a full composite thing

In a way there wasn't a lot of lobbying about the disability stuff, the majority of the lobbying was centred on the sexual orientation stuff.

“If it had just been a disability thing would it have gone through without a murmur.... I don’t know”

PC: My feeling was at the time that the disability sector was very happy with the ‘broad church’ approach

I think we wanted it all to go through, the coupling was just the timing of the legislation

Q; Fact that disability wasn’t included in BORA and Min of J Doug Graham signalled to disability community that he intended not to include disability in HRA, was HRA the last chance for disability community to get a piece of HR legislation?

PC: it was an opportunity, take the opportunities to do as much as you can at the time, right, hit the nail on the head, the opportunity was there,

There was quite a powerful lobby of people with disabilities in those days, DPA was very powerful, and it actually had some very strong leaders on it, Byron Buick Constable, Quentin Angus, Russell Kearse, JB Munro, Paul Curry, it was a reasonably powerful body and when it wanted to meet with Ministers it was listened to.

PC noted that the current Disability community has splintered since then and is not the same powerful lobby; although we have a HR Commissioner [Paul Gibson] which I think is fantastic,

In those days the disability sector was very well connected, we had marches on Parliament, petitions drawn up about our HR handed to the Prince of Wales when he visited, a whole march from Lower Hutt to Wellington, a whole bunch of activists chained ourselves to the rails on the stairs of Parliament,

Activism driving the message that the disability community was heard, it was also the decline of the charity model and the rise of the social / citizenship model that was the time of the change

We had people coming out from the States to talk about it off the back of the Vietnam War, the ADA was being developed and going through, DPI / DPA / RI / Coordinating Council for People with Disabilities, were being formed, DPA formed 1983, we were a pretty strong voice

Q: the fact that there were strong voices within the disability sector and bureaucracy made an impact?

PC: I think we were listened to because it was a well connect quite powerful lobby, I think it still is there but it's splintered today, I see the rising of it again, I see embryonic shoots of it as we see unfulfilled wishes there

Q; Recollections of PC's time with DSS during the passage of HRB

PC: I found Katherine Reagan's approach, non-discriminatory, she was wonderful to work with, her biggest issues was trying to convince others, colleagues, it's always the way, a passionate minister really understood that this really could make a difference for people with disabilities and those with regard to sexual orientation, she just saw it as unfair, and we felt the same so we had to write cabinet papers , briefing notes for her use with her colleagues to convince them that they should actually go the same way, because there were about an equal amount of people not in favour, it's not a huge vote catcher, [the HIV issue]

Fascinating to be able to push a HR issue in a political sense when certain ideologies were more concerned over where this was going to cause me to lose votes

The clauses themselves were pretty dry, it was trying to win the hearts and minds

Q: Did you see KoR as being personally connected to the issue?

Yes,

Q: What drove that connection?

In my mind I think she was a decent person, with a decent heart, it probably was the number one thing in her term of office, maybe the time she was in Parliament.

Q: it has been suggested that KoR knew she wasn't coming back to Parliament, she had nothing to lose, and she could pick an issue she could not have picked if she was going to seek re-election?

PC: Never really saw that or felt that at any time, there the reverse side of the coin, If it had all turned to custard you leave yourself with a legacy not to be proud of

There's one thing for sure, everyone who goes into Parliament goes in with the intention to make a difference so at the end of your time you want to be able to say, this is my legacy

PC she was also a great champion for other things we were trying to do at the time in support services, coordinated approaches to things, a lot of them never came to fruition more the implementation than the wish

Q: Your Role of Manager DSS, did it impact on the work you did with relation to the HRB?

PC: No I don't think so, it's interesting being a public servant, it's interesting how you operate as a public servant within areas of politics, take for e.g. your owners as major stakeholders is the Minister, my purchasing boss is the Minister, my moral owners are the families / whanau that I'm here to serve and the tax payer that pays the tax.

All the rest in the middle is just transferring tax payers money, comes from the tax payer, goes through the big machine gets divvied up and divvied out.

My job here is to make sure that it gets back the right way to help the constituency I'm here to serve

When working at DSS my moral owners were people with disabilities, of course I was one of those too, I still am, my heart was still in it, I was still involved with DPA at the time, we had set up a large disability group forum, about 100 groups, where we used to bash issues round and round, try and work out ways to get things sorted,

The whole 'New Deal' a new design way of how services should be put together and operated which was never fully implemented properly, because the changes to the Health system [RHA, HFA funder / provider split / contracting out] all sabotaged the implementation of the New Deal

Individualised funding, separating out coordination from assessment, they get conflicted, and separating out the purchasing, if you look at what Tariana Turia is doing with Whanau Ora with establishing a separate purchasing agency, she's almost back full circle to what was present in 94/95/96

PC: I think I would have been disingenuous to put my role as Manager of DSS ahead of my own disability; it was too ingrained by that stage.

Interview with Mike Gourley, conducted at Radio New Zealand, 4/ 5/ 12

Common Ground?

An educational campaign that went around the Human Rights campaign, important to bring together representatives of the groups who were represented within the HR legislation as being discriminated against, as all had 'common ground'

Work together to put pressure on the politicians to actually do something

In the early 90's Gourley was working for SSC, put the idea of a CGC through the disability networks and received a positive response, Alison Risborough, (DoL) was involved, used to have meeting in the Dept. of Labour

CGC was launched at the Nat Lib, a huge occasion

Public campaign

"Felt it was more likely that we would be included if we got the public supporting us as well"
defiantly a unity in numbers

"The thinking was that if the public became more aware of the issues they would put more pressure on the politicians"

Over the months that it took to organise the launch, the two communities, Gay / lesbian, HIV and disability built a definite solidarity

Strategies CGC used to the public

- Launch
- Press releases
- Forums led by Robyn Hunt

'Most proud of'

That DPA had got in behind other groups where there was initial prejudice and were seen to be leaders on an issue

Getting involved on systemic change as opposed to piecemeal issues, an overall view of the organisations role

Having a focus, galvanised Wellington DPA, but is not sure how much the HRA campaign got out into the regions?

Concluding Remarks

Joint interest in shaping the HRA, an injury to one is an injury to all was very much the perspective, if anyone group was being excluded, all were being excluded.

Tension between the social liberals and the politically active that were socially conservative

Interview with Anne Hawker, conducted at Ministry of Social Development, Wellington 28 /
3 /2012

Beginning of the Disability movement in New Zealand

AH: Have to go back to 1978 to the creation of the Coordinating Council and RI NZ, representing all stakeholders whereas Coordinating Councils was a Govt appointed body, it was in the mould of deciding the policies for disabled people

Byron BC, JB Munro, had a key part in stating that there should not be two separate bodies, to bring forward ideas, used the basis of DPI / RI, 50 % had to be service providers, 50% had to be disabled people, meant that the service providers they had to have disabled people as their representatives to gain representation on the new body, an opportunity for corporate and individual membership

An opportunity for vigorous debate, to get all the issues out and gain consensus, one of the things that has changed since DPA has moved to 100% disabled people is the missing of robust debate, means that a co-ordinated point of view is missing from the sector

IYDP

Looking at the players at that time, it was still society doing to disabled people, with a few high profile disabled people being used as front people, in Dunedin, Barry de Geest was the

front person of IYDP committee, Ann came in as Chair of the committee, that worked quite well. What it was looking at, IYDP looked at was raising the barriers to participation,

What also happened in New Zealand at that time, independent of the US was the development of the ILM. The movement was led by women, came from a community development model, making a difference in people's lives as opposed to a service provision model. ILM women would sit at the back of DPA meetings and have very robust debates, a 'vibrancy' of debate.

AH was in Brazil, a woman gave a presentation on what the world was like in 1981, AH gave a presentation in Dunedin on the same topic as she feels the history of disability movement is being lost. In 1981 disabled people didn't know they could get alteration to their homes, work was through the sheltered workshop scheme, education was limited, and some who made it, despite the system.

Specialised services for disabled people how does that interact with mainstream services, no thinking about the interaction, argument centred around the cost of the specialised service. 1981 saw specialised services being set up, and a movement towards facilitation of access to mainstream society.

Development of DPA may have been a catalyst of 1981 but also was what was happening organically because of what was happening within DPI as a result of the walk out of the Winnipeg conference.

Women leading the ILM Movement: Women in disability movement in New Zealand

Had a women's caucus at one stage, have always been strong women within the disability sector, Robyn Hunt, Wendi Wicks, Bronwyn Hayward, there are some that have felt that the women's voice had not been felt

WDA come from a feminist approach as opposed to a disability approach, different dynamics, as a result of 1991 DPI congress DPI Australia imploded while as a result of the 1996 DPI congress DPA NZ was made stronger, so different power dynamics going on with the groups.

There were some arrogant men e.g. Robyn Hunt, Wendi Wicks, were not going to be pushed over, unlike Australia in NZ women were in leadership positions.

Had interesting discussions with Ministry of Women's Affairs, when Mary O'Reagan was there she was fantastic, but later the Ministry put disability into a more administrative category

There was incredible energy and passion at that time, robust discussion, Mike Gourley as a 'Trotsky'

A friction around what to advocate for between older generation and younger generation, managed care

People with acquired disabilities vs. people born with disability and the hierarchy of disability

E.g. of groups going off and fighting for a single issue, Paul Gibson advocating for Blind benefit when he became DPA CEO, AH had to remind PG that DPA was a pan disability group that the reduction of poverty for all disabled people was the goal of DPA.

The Accessible Bus campaign; the initial strategy by the HRC to adopt three complaints instead of taking a class action against Stagecoach was in the opinion of AH an error of judgement that lead to the failure by the HRC to make large scale progress on the issue of accessibility on public transport.

When discussions happened in 1983 DPA talked to HRC about the issues, AH talked about an 'immaturity within the sector' about seeking mana on a particular issue, while losing sight of the grand picture / strategy.

AH when the sector works together in a coordinated way "big things" are possible, when the sector splinters off seeking to increase its individual mana on projects that benefit an individual group the sector is divided, uncoordinated and not moving forward together

1990 BORA

AH not an issue for the disability community, the mistake the disability made was not to understand BORA for what it was, not to unpack it

Economic and social rights are as important as political and civil rights from a developmental point of view, as implemented by CRDP

DH made point that CRDP implemented economic and social rights together with political and civil rights, WW made the point that BORA not a hot button issue,

AH: didn't understand its potential, as a result of sector immaturity

Gary Wilkinson and AH gave presentation around CRDP could see that there was a big gap in the sector of knowledge on the CRDP, need for education on the role of CRDP, no connection for people with disabilities about the role of the convention in their daily lives

People First done great job in area of employment rights making the issue of individual employment agreements rights for people with intellectual disabilities

AH challenges PF to take the learning's from employment to areas such as health, can manage personal health management using personal health agreements

At that time people had big issues around accessibility that were really big issues, BORA was missed as an issue

Sir Douglas Graham comes to disability community states that, it is his preference that disability will not be included within HRA

AH part in DPA lobbying to get disability amendment

Executive worked out the policy position, policy position was it was going to be inclusive, no matter what, include all aspects,

Needed to inform the HRC of the potential pieces of work that would come out of the new legislation, needed to address some of the fears being put up by the insurance council,

Did a risk assessment against those likely to do DPA disfavour.

QA was instrumental in providing the technical knowledge around disability, that's what the sector doesn't have at the moment that real technical knowledge combined with real advocates.

The combination of AH and DH arguing the advocacy aspects and QA answering the technical legal aspects was necessary to be successful.

AH role was oversight, making sure everyone was on track, communicating with DH making sure everyone was on track

Interview with CC, comment Parliament understood disability better than AIDS at the time

AH agreed, had been doing that sort of work for some time.

Grouping of disability community with AF

It was broader than the AF, DPA took the risk, AH commented that there was robust debate as she had to facilitate it

AH had to keep to the issue and principle not getting emotional, making sure that people's personal opinions on gay / lesbian people clouded the debate

AH was totally clear on the fact that DPA needed to go to the Exec with a unified position, AH had to remind the Exec of the direction of agenda, keep people to the principles

DPA made the decision not to advocate for ADA style legislation, for positive discrimination or affirmative action as DPA wanted an inclusive piece of legislation that included all people experiencing discrimination not a separate piece just for the disability community.

The entire sector was involved in the lobbying, not just the Exec of DPA, but the entire sector

HRA initiated by the disability community, by the ground up, whereas BORA the expression of an academic argument from Sir Sir Geoffrey Palmer

If we aren't counted, we don't count - Slogan regarding the 1996 Census and disabled people

Differences between DPA in the past and in the present

Leadership of DPA was much broader; it stayed for a short time then left, went in to do something then left

Did not have the robust discussion with all parties

No strategic plan about what they were going to concentrate upon, what were the things that were going to make a difference

Haven't got the mandate to do the coordination between the sector groups, AH remembers talking to ABC (Blind) they said you cannot talk on our behalf, AH was advocating coming together and facilitating a common approach

Groups would claim they would want to advocate for their individual issues, AH said that was fine DPA would help and support but on the big issues such as the Census in which changes affect the whole of the sector the changes have to be made together, "because its only together that we can make a difference"

There are too many groups, causing confusion between advocacy and service provision, e.g. the deaf community who want to be both a member of the disability community and a service provider for deaf people

A lack of clear leadership,

RH and AH gave a presentation on governance to DPA most of it went over the organisations head,

DPA met with Winston Peters and Jim Anderton prior to the election 2011, to talk about prioritising disability, making a difference, come with 2-3 issues, a clear agenda and a plan of how the politicians can help.

AH view that Mike Gourley got to close with previous Minister of Disability Issues Ruth Dyson, they weren't prepared to ask the hard questions

AH would like to see a set time limit on leadership positions within DPA

Interview with Dave Henderson, conducted in Newtown, Wellington 21 / 03 / 2012

1981

DH: wasn't around in 1981, was working as a transportation planner for Auckland regional Council, came in the latter stages of all the changes, was employed by DPA in 1984, JB Munro, Byron BC, Quentin Angus had got together the separate groups that they represented and made a decision to form an organisation using the constitution that Quentin had put on the table, they elected a board, with Paul Curry, Bryon, Hired DH in 1984.

Telethon

DH: it provided a seed fund for teletext, now there is so much online, at that point there was no alternative,

There was a huge diversity of applications around information systems; the decision was made to invest in the one, teletext,

The other big area was around transport, 100's of applications, none had provision for depreciation, training of drivers, safety / security, maintenance, oil changes etc, the decision was made to fund one system, total mobility through the taxi system as they had all the systems in place

Tax payer funds were going into public transport, the argument from local authorities was disabled people are not tax payers, DPA argued disabled people pay rent, which goes to rates, also an amount of disabled people do work and pay tax

1987 issues finally got recognition that disabled people were citizens in terms of access to transport, start of a rights based approach

Telethon: the ends justify the means?

There was a degrading element to the advertising, there were a lot of degrading aspects to the dominant culture of how disability was portrayed at the time that is not present now.

Robyn Hunt had huge role in changing the way society changed the language society used to describe disability.

E.g. when retailers say that they never get disabled people in their shop, people from the local DPA committee say the door is up steps and there is no accessible transport to the shop. It becomes stark at that point

Change within IHC / CCS how disability was portrayed, telethon was not a stand out, it was part of the way disability was portrayed at that time

It was a reflection of the dominant cultural norm at the time

Telethon only one of the IYDP events, that changed culture, just the most visible, it had the profile.

Change in culture from charity to Human Rights

DH going through the change myself as a regional planner for my skills as a planner, but I could very quickly see through talking to people like JB Munro / Russell Kears, (Mentor), Russell was ahead of the game, trying to change the organisation from within, Paul Curry wasn't prepared to accept systems as they were at the time.

Quentin Angus, a lawyer, made a huge amount of submissions on bills,

Quentin very keen on legislative change, when DH made CEO of DPA worked closely with QA QA focussed upon changing the law of the land, and re-educate the people

Ken Munro had not been so keen on the legislative change approach

DPA in Brandon St, already preparing to make submissions, a partnership that lasted QA lifetime.

Drafted submissions on anything that affected disability, submitted orally and in front of committee to persuade the committee on the case of disabled people, building relationships with politicians.

Always ask to be there in person, assert the issues

Which is why when Sir Geoffrey Palmer put the kybush in anything in the Bill of Rights we did do some work to him, we wrote, but ultimately he was ultimately he was adamant,

DPA's argument against Palmers argument if you take a whole of society approach then the people who are at a disadvantage from the start through no reason of their own,

Government has a greater responsibility to ensure their participation in society, he didn't buy it,

Huge political football around affirmative action from the US, Parliament didn't see any need for it

Around the right to participate requires positive action from Government

Focussing on Bill of Rights, as had been "doing it piecemeal" up until that stage, could argue with this Select committee on this topic or that committee on that topic, could be there for decades and make no progress

Why when Kathryn O'Reagan came along she had people from AF to help with the numbers,

Quentin Angus was reluctant, he felt that Parliament would buy the disability argument but wouldn't buy the Aids argument

Big arguments over that, DH won over as Chief Executive

AF had skills DPA didn't possess

"Parliament understood disability more than it understood AIDS" comment?

Yes, the work we had been doing, DPA's lobbying there was a pay off there,

Joining up of the Aids lobby with DPA, political risk Quentin position

To pass the legislation requires a 'broad church' of groups in favour of the legislation

My motivation to apply for DPA CEO was about addressing the amount of discrimination in NZ, DH was comfortable with working with the AF but was aware that there were people that were not comfortable, was about Human Rights,

Were more likely to succeed if we DPA tied ourselves to the skill set of AF, resources, nation structure of voices to MP's, a Package that could not be denied,

AF brought in a 'presence' so that the lobbying could go to MP's and get meetings that DPA could not get as a single group.

An MP could deny that Human rights belong to people with disability but found it much harder to deny that they could belong to the larger group of disable people and people with AIDS and Gay people.

It becomes an unassailable argument at that point, to make an argument that MP's could not argue against,

Within DPA there was discomfort against the grouping with the AF, but the reality was that when it was discussed at NEC level the majority decision was to proceed with the grouping with AF.

Discomfort occurred at the concept of the alliance with AF, culture at the time, which was that Gay people were on the outer, there was discomfort, whether it was

After HRA, Quentin and DH got a better hearing on issues such as the Building amendments after the HRA, we still didn't get everything we wanted but we got a better hearing because Kathryn had enabled a new paradigm of lobbying to Parliament from grassroots which in the early nineties was pretty radical

DPA was at the forefront of that, it changed the interaction between Parliament and the people, something quite significant could be achieved by outsiders

DPA then and now

A vision

A visionary activity that people can come around, and be motivated by and do something significant with that vision, otherwise people drift away

Discussion of vision and sharing of the vision,

Media relations

Disability presented better now, compared to IYDP, disability / ill healthy presented in negative way

Relationship good, get column inches, but way disability is presented is still negative

In 1981, media got all excited, presented lots of stories, but there were lots of holes in terms of the language of how disability was presented, suffering was were the media used language out of ignorance to present disability

Now, the language is better, due to Robyn Hunt, education efforts but the language was 'crude' in 1981, the language has moved forward from 1981,

Interview with Robyn Hunt, conducted at Victoria University of Wellington, 29 / 3 / 2012

RH: Economic, social inequality are very much factors that disabled people are a part of and are on the down side, that has to be weighed against the legislation [HRA]

Legislation is very important, important as it creates a framework, but by the same token it can be undermined in a whole variety of ways, usually by lack of resources

The other thing that happens in Government is a real lack of institutional knowledge / history through restructuring of the public service libraries vanish so too does the knowledge, a whole lot of history went

Generations of public servants do not know how to engage with the disability community

Part of the problem is through a lack of knowledge but also through a lack of accountability to the legislation

RH: No decent data collection, in the 1990's there was a surge in University attendance by disabled people; the MoE doesn't keep statistics on success / failure by students with disabilities

RH: "this is part of an underlying ideology around ambivalence toward disabled people failing and a worry that disabled people's failure will drag down the other figures"

The data that is available is not being used, and there is very little data anyway

Inquiry into Accessible Transport

Only one local body using the information from Census, “with an aging population and a rising disability rate the issue will not go away”

RH “politics are not as simple as they used to be, not just left and right, with MMP different parties different kinds of alliances”

Interview with Wendi Wicks Chief policy coordinator, Disabled Persons Assembly,
conducted at the offices of DPA 27 / 3/ 2012

Q: 1981 IYDP, its effect upon disability community in New Zealand and then upon DPA

WW: Wasn't actually an active player, my connection was through hearing from those who were an active part are reflecting from their part in it,

It appeared to have a profound impact, not sure whether that was due to getting more money in, due to the Telethon, more money for DPA

More money for people to dream , or for people to realise past held dreams

My understanding with RI, DPI, Coordinating Councils; all becoming actively focussed around the idea that we came do this,

IYDP had the effect of enabling Disabled people to take the lead, whether or not Anne Ballin was a figure head, AB commented to WW that she felt she was added on afterward, as a bit of a figurehead

There were other DP, everyone was running in the same direction, in parallel, 'we can do this for ourselves'

Q: the telethon experience: did the ends justify the means?

WW: In my judgement the ends did not justify the means, however there are a lot of people who see the money and whose need is great and are convinced by expediency, people are convinced by the possibility of having life a little bit easier / normalised,

“If life is a struggle and someone offers them a way to make it just that bit easier then the ends to justify the means”

DH was of the opinion that the positive outcome did justify the portrayal,

WW: the immediate gain did not address the portrayal of the stereo types of disabled people and the portrayal of DP of objects of pity

DP are still ‘the other’ are still portrayed as ‘receiving’ despite the fact that the other may be a little bit better off

Q: how does the IYDP event sit with the change from a charity model to a HR MODEL?

WW: Actually it didn’t come from the Government side, it came from DP strongly critiquing Government policy, Robyn Hunt strongly involved in this.

Government didn't change view on delivery of Disability policy, had to be pushed every step of the way. More than a little bit gratified when Govt announced NZDS, but still wanted a non DP on the committee of NZDS

Government, as a strategy, took path of least resistance, 'what would it take to get them off our back'

WW described the policy consultation process as one where Govt consults but has an attitude of knowing best about to deliver policy to disabled people, what is 'best' for disabled people.

Q: What role cost reduction play in Government policy toward the disability policy?

WW: Health Welfare interface, Upton, redefined services to ring fence demand, to reduce demand, to reduce cost. Cost savings via needs assessment.

Government "Talked the social model talk, but walked the medical model walk", they walked the neo-liberal walk as well, and the neo-liberal /medical model had a reasonable fit

Not dissimilar to current UK plans by David Cameron to do away with the NHS, the 'raw deal, new deal'

Q: DPCW Act 1975 a cost based decision rather than an ideological decision around disability

WW: no idea what the cost of providing for disability services, different amounts for different Boards, different criteria.

No data around cost, didn't keep data around the cost, when people moved out of Porirua, no idea what it cost to run the facility, the disability sector had nothing to base funding upon

Telethons are a 'cruddy way of getting money, the Gerry Lewis, experience, you have to sit up and perform like a performing circus bear"

Q: lead up to the Bill of Rights 1990, DPA lobbying

WW: Fairly muted, people didn't see it as having influence, some issues grab people by the throat, legislation is a difficult one, particularly constitutionally law

Q: Inclusion of economic and social rights within BORA, discussion within DPA?

WW: Do not, WW was Wellington Secretary, did not feature, not a hot button issue, Palmer did not excite DPA members about the issue.

Nobody took the time to unpack BORA; it's not the most 'accessible' document,

The nearest thing DPA got to getting excited over BORA was in 1996 when during the lead up to the Consistency 2000 project, they were going to make changes to HRA, s.151, except for employment, everything went to a BORA discrimination standard 'fair and reasonable'

Somewhat muted

Q: HRA 1993; Personal Involvement in DPA lobbying for disability amendment

WW: a long time coming, Kevin Whittaker, a DPA member from Whanganui, organised a petition to get the clause in the first place. Can blame the likes of J.B. Munro for the fact it wasn't there in the first place, he said "it didn't need to be because we will look after disabled people"

What drove it was the fact that there were so many complaints that we couldn't make.

Experiences of discrimination had bitten into people's souls and here we are not in the Act, particularly in relation to work, it so big

Constitutional law doesn't get people excited but the lack of rights does get the disabled community very excited

WW characterises the strategy as the Elephant gun approach

Broad siding from a lot of directions, but the message is 'we want disability into the HRA'

Common Ground Coalition Mike Gourley (Disability GLBTG, Trade Union) 'conspicuously successful'

Disability community had seen itself as isolated; saw itself as part of a wider community.

Commonalities with struggle for Women, Maori rights, GLBTG, a good exercise to place disability within a wider community of struggle

A nice bit of lobbying, a fair bit of the Saul Lynsky's 'go have fun' a fair bit of fun was had while at the same time busting stereotypes around disability, isolation

Still only part of the disability community was representing the disability community, the stereo type of disability was / is people in chairs and visual impairments.

Mike Gourley was very articulate, he was not representative of the whole disability community, but made the able-bodied community safe with interacting with disabled people.

People could consider interacting with someone with a speech impediment

Mike, by being the person he was, allowed the next person to be accepted by laying the foundations of acceptance

DPA peppered Ministers Doug Graham

National / Labour Members of Parliament

Talking to Ministry of Health, Justice, High Officials, Low officials, anyone who looked like they could help, doesn't think anyone approached Palmer over HRA

Q: Grouping with AF, uniformity of coalition?

A certain level of disagreement, like the right to life debates within DPA, there was a range of opinions, not everyone was united, not everyone was comfortable with Gays and lesbians and there were conservative opinions about trade union type people, 'bolshy lefties'

The issue of the right to inclusion within the act rather than temporary bedfellows, we weren't entitled to make moral judgements about

Q: Charles Chauvel: Parliament more comfortable with disability than AIDS

Disability more picturesque, safer

Q: Why coalesce with a partner that could reflect negatively upon DPA?

It wasn't so much a campaign that originated from DPA, it was originated by DPA members,

Mike talked to Dave about the idea of the amendment, Dave talked about who would be good people to work with, it wasn't as if there were people falling over themselves to join with DPA.

National office didn't make the campaign up at national office, nor did NEC

WW didn't remember receiving negative feedback on the decision to join with AF

Final thoughts

History of DPA will inform where DPA goes in the future

Successful campaigns have been driven by disabled people driven by an issue 'walking the talk' don't wait for permission

Appendix Two

Consent forms from interview participants

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