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# **The Disabled Persons Assembly**

**1983 – 1999:**

## **Successes, Challenges and Lessons for the Disability Movement in New Zealand**

*A thesis presented in partial fulfilment of the requirements for the degree*

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## Abstract

This thesis presents a case study of the development of the Disabled Persons Assembly (New Zealand) Inc. since its inception in 1983. The research methodology used was the topical life history approach. Archival research and an analysis of relevant policy documents, which contextualize this history, accompany the life history approach. Participants worked through a semi-structured interview schedule with the researcher. A range of topics was explored, including participants' views of the organisation's philosophy, goals and objectives, successful projects undertaken by the organisation, its leadership, current issues for the disability movement and future directions for the Disabled Persons Assembly.

It is argued here that the Disabled Persons Assembly has been a focal point for the disability movement in New Zealand, and provided this movement with an organisational structure. An analysis of the development of the Disabled Persons Assembly is presented that incorporates reflections and interpretations from the six National Presidents (or their surviving spouses) from 1983 to the present. The participants provided personal knowledge of events that occurred at different times during the organisation's history. This thesis provides an insight into the significant contributions that these people have made to both the organisation and the wider disability movement, showing that each approached their term of presidency with a passion and strong commitment to working with others to achieve and uphold the rights of disabled people.

Social Construction Theory, Social Oppression Theory and the work of Michel Foucault have guided the development of theoretical frameworks used to analyse the data. An analysis of the organisational development of the Disabled Persons Assembly identifies challenges that the organisation and its leadership addressed as it continued to grow. It is argued that from 1993 onwards the Disabled Persons Assembly leaders have focused on developing and maintaining the infrastructure in order for the organisation to survive. This coupled with a lack of ongoing debate around definitions of disability and a lack of clarity of the organisation's own analysis of disability has resulted in an overall lack of direction. In conclusion this thesis argues that the challenge for the Disabled Persons Assembly is to reposition itself in order to again take a leading role within a vibrant, challenging disability movement that is working for social change.

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## Preface

### Who I Am

In order for me to begin writing this thesis it is important that I clearly locate myself in this project, and in doing this, explain why I chose it.

I was born with my impairment, a condition known as Congenital Amelia (the absence of all four limbs). This has significantly impacted on the life choices that have been available to me. This is not just because of my physical limitations, but is also due to the infrastructures in New Zealand society that determined the level of supports available to me in the areas of education, health, disability support (ie. caregiving services), transport and employment. These systems have sometimes supported and sometimes impeded my progress at various points in my lifetime.

My parents are farmers and I am the eldest of five children. Being raised in a rural area often contributed to the stresses my family experienced with having someone with a disability, as the services I required were usually not available as they might have been in the towns and cities.

It was very difficult for my parents when I was born. My parents talk of the doctors organising for me to be placed in residential care (without their consent) and being told to "try to forget this ever happened". My first two years of life were thus spent in the Home of Compassion in Wellington. My mother often reflects on this period, saying that she felt like she had never had a baby. My situation was not that unusual for that time. The birth of a disabled child was not seen as being something that should be celebrated, rather it was seen as being a tragedy, both for myself and for my family. There were no supports offered to my family if they were to keep me at home, rather, the response to our needs at that time was to offer institutional care. Eventually my parents decided they would take me home and raise me in a "normal" family environment.

I was able to attend the local primary school where I was fully integrated into all aspects of school life with the support of the teachers. There was no outside support available (ie. teacher aides, specialist equipment); my school attendance happened well before the days of mainstreaming policies.

As I approached adolescence the situation at home became more difficult. My mother was expecting my youngest brother and found it increasingly difficult to lift me and meet my personal care needs. Also, they were aware that it was going to be difficult to have me attend a secondary school in the district as there were no accessible schools at that time, no teacher supports were available, and there were difficulties in getting transport to get me to school and home again. It was therefore decided that it was necessary for me to go and live in an institution for physically disabled people (Pukeora Home). It was at Pukeora that I got my first motorised wheelchair, attended secondary school through the Correspondence School, and learned to assert my needs. It was also where I began to develop an awareness and understanding of inequalities that existed in our society, and to question why there were so few lifestyle options available to disabled people. I stayed at Pukeora for ten years. Near the end of my time there, as I was preparing to leave, I heard of an organisation that was being formed called DPA, the Disabled Persons Assembly.

Six months after I came to live in Palmerston North (living in another residential facility, Ryder Cheshire) I was given the opportunity to attend the second Annual General Meeting of DPA in Hamilton, in May 1984. I remember feeling quite overawed with the number of disabled people there, of the anger evident as people expressed the disadvantages they had encountered in trying to access education, employment opportunities, housing, health services, and a reasonable level of income to meet their needs. I was also excited about being involved in an organisation where disabled people were challenging structures and attitudes, confronting politicians, and beginning to identify alternative ways of organising things to more appropriately meet our needs. In September of that year the Palmerston North & Districts region of DPA was established, and it was then that I really became involved. For the next fourteen years I held a range of positions in the Regional Executive (Palmerston North & Districts), including women's coordinator, vice-president, and in 1995/96, president.

As a disabled woman who has been involved with other disabled people and disability support service providers, as well as being involved with DPA almost from its beginnings, I am more than just a neutral outsider. It is my intention therefore to use personal pronouns instead of referring to 'the researcher'. This preference stems from an underlying feminist analysis that advocates that I, as the researcher, have a direct relationship in this project and not just as an objective observer gathering data.

## Why DPA and Its Leadership?

My membership in the disability community and long-term involvement with DPA certainly place me in a privileged position to undertake this project. I was inspired to undertake this study after reading two books.

The first was Sandra Coney's *Standing in the Sunshine: A History of New Zealand Women since They Won the Vote* (1993). In her introduction Coney explains how this book marks and celebrates the centenary of women winning the vote in New Zealand. She discusses how the book is broader than just the suffrage struggle, that it "embraces all aspects of women's lives through the past 100 years - from the family and intimate relationships, to the workplace and the sports field" (1993:10), tracing the changes that have happened in women's lives over the past 100 years. As I read this book I marvelled at the strength and courage of the individual women and their groups and organisations as they worked to achieve change in New Zealand, and how their efforts became beacons to women in other parts of the world. However, by the time I reached the end of the book I was extremely concerned that there was not one profile included of a disabled woman and her achievements. The contributions of disabled women were completely invisible. This thesis does not focus solely on the achievements of disabled women, (although such a project is certainly long overdue). It is my intention to begin to locate disabled peoples rightful position in New Zealand's history, recognising their contribution not just within the disability community but in New Zealand society as a whole.

The second book was Jane Campbell and Mike Oliver's *Disability Politics: Understanding our Past, Changing our Future* (1996). They explain that it should not be seen as a history of disability, or of the disability movement. Rather, Campbell and Oliver state that it is a "presentation of a series of perspectives on the process of self-organisation of disabled people that has been occurring over the last thirty years" (1996:17). I found this book to be particularly powerful because Campbell and Oliver enabled disabled people to tell their own stories, and the stories of their groups and organisations of which they were active members. It enabled people to reflect on the development of a particular organisation, the British Council of Disabled People, and to reflect on the future directions for that organisation and the wider disability movement in Britain. When I reflected on my own experiences as a member of DPA I was able to relate many of the British trends to the New Zealand scene. I became convinced that

this kind of research was needed in New Zealand in order that disabled people here might also be able to relay their own histories, and reflect on directions for the future. It is my firm belief that only by listening to the stories from the past and learning from those lessons can we move forward and plan effective action now and in the future.

I see this thesis as being but a small beginning in outlining some significant contributions and achievements by disabled people in New Zealand. This thesis is considerably smaller than the two projects discussed above. However I hope to provide some insight into the characteristics and achievements of six individuals who committed a large part of their lives to working alongside their disabled peers through their involvement with a wide range of organisations including the DPA. I will include an examination of their contributions during their respective terms as the National President of the DPA. This thesis will also explore key issues facing disabled people today, as well as key issues which I believe are facing the DPA and need to be confronted if the organisation is to have a future. By setting these issues and an analysis of the development of the DPA within a theoretical framework I hope to promote renewed discussion and debate within the DPA and the wider disability community in New Zealand as to future directions for political and social action.

# Chapter 1

## *Introduction*

The Disabled Persons Assembly (New Zealand) Inc. was formed in 1983. It comprised of two organisations, Rehabilitation International New Zealand and the New Zealand Council for the Disabled who merged to provide a structure for the new organisation, and an ad-hoc group of disabled individuals who at that time were looking to establish Disabled Peoples' International in New Zealand. The DPA (as it will be referred to throughout this thesis) is a national 'umbrella' organisation that promotes itself as the "speaking voice of the disabled" in New Zealand.

I have personally been actively involved with the DPA since 1984, attending National conferences and meetings, and having held various positions over a period of time with the Palmerston North & Districts Regional Assembly. As a disabled woman with long-term involvement with the DPA I was in a privileged position to undertake this project.

This is an opportune time to reflect on the development of the DPA. There are political and financial pressures currently facing the DPA as an organisation. It is important for any organisation involved in political and social action to review its history. I hope this thesis might contribute to the review process of the organisation's current position, and that it will promote discussion and debate as to future directions for the DPA and the disability movement in New Zealand.

My research focus was to develop an understanding of the development of the DPA as part of the disability movement in New Zealand from the point of view of the individuals who have been active in that movement. The objectives of the research were to:

1. Trace the development of the DPA in New Zealand
2. To locate this development in the wider picture of social/political and economic developments in New Zealand
3. To identify key people involved in the development of the organisation, and
4. To explore theoretical ideas that are useful in examining the experience of the DPA in particular, and the experiences of disabled people in general.

An analysis of the development of the DPA is presented using archival records and publications, as well as drawing on the reflections and interpretations from the six National Presidents (or their surviving spouses) from 1983 to the present. The participants provided personal knowledge of events that occurred at different times during the organisation's history.

The data is organised into the following themes:

- Historical overview of the DPA
- Philosophy, values and beliefs of the DPA
- Leadership (including individual profiles)
- Successes and ongoing issues for the DPA as part of the New Zealand disability movement
- Future directions

These themes provide the base for my chapters and a framework from which to present my discussion and analysis, and to relate my findings to relevant literature.

## **Format of the Thesis**

In chapter two I discuss the theoretical frameworks I have used to analyse the development of the organisation and to examine its role within the disability movement in New Zealand. I begin by outlining Social Construction Theory in its broadest form, and then examine Michel Foucault's theories of power and knowledge, with his focus on power relations in Western societies. I then go on to explore Social Oppression Theory which has been developed by Michael Oliver and others (Barnes, 1990; Finkelstein, 1980) to challenge the marginalised position of disabled people in many Western societies. This leads to an examination of the social and political actions of disabled people with the emergence of the disability movement as a social movement. Finally, in order to understand the stages that the DPA as an organisation has passed through in its development I give a brief overview of a model outlined by Bartol, Martin, Tein & Matthews (1998). This model identifies the life cycles organisations pass through and the changes they need to make at each stage in order to survive and grow. These theories provide a framework from which to build an understanding of the development of the Disabled Persons Assembly in New Zealand, and to relate the development of

this organisation to the wider disability movement. I have chosen these ideas, not because I think they provide all the answers but because they present concepts and ideas that help me to begin to make sense of the experience of disability, and to analyse the experience of the DPA as a developing organisation in the disability community.

Chapter three outlines the methods and methodology I used to research the development of the Disabled Persons Assembly. I have used a case study approach to examine some of the key events that led to the organisation's forming and its activities from 1983 to 1999. I have drawn on techniques encompassed in the topical life history approach. Because of the time lapse from when events occurred to when my research was conducted it was sometimes difficult for the participants to recall a lot of information. Archival records and publications produced by the DPA are therefore extensively referred to in my discussions of events that led to the forming of the DPA and of its developing structure. The six National Presidents (or their surviving spouses) of the DPA since 1983 participated in a semi-structured interview. I chose to focus on those who had held this position as they had a clear understanding of the beginnings of DPA, presented a range of perspectives and interpretations of the development of the DPA, and were able to articulate the issues. The participants discussed the values and philosophies of the organisation and then outlined their involvement in the DPA. They reflected on achievements during their time as National President and discussed past and current issues for the DPA and the New Zealand disability movement.

Chapter four outlines events that led to the forming of the DPA in 1983. It is divided into two parts and outlines the early history for the disability movement that led to the development of the DPA. Part A sets the scene, giving a brief overview of historical approaches in responding to the needs of disabled people from the early colonial times through to the 1980s when DPA was formed. It gives an analysis of the development of DPA within the context of the wider social, economic and political factors that motivated individual disabled people and groups to establish an organisation that would work to bring about change. Part B outlines events that took place in the initial stages of the formation of DPA. Material for this discussion has been drawn from primary and secondary sources such as Tennant (1996) and Gregory (1995), publications from the DPA such as the Able Update magazines and from interviews conducted for this thesis. I have also incorporated some of my own personal recollections of the socio-political

conditions that motivated disabled people (myself included) to begin speaking out on issues that affected us.

In chapter five the structure, role and philosophy of the DPA as it is today is examined, and the value base of the organisation is explored. The publications from the DPA show that while the general structure has changed little since the DPA's inception, the role of the organisation has evolved over time in response to a changing political environment and the needs of its membership. I have used information from the DPA's Constitution and Rules, its Policy Manual and from its website (<http://www.dpa.org.nz>) to examine its structure and role and in my discussion of the philosophy and values of the organisation. In using these contemporary sources I have chosen to retain much of the ordering of topics that is used in the DPA publications in my own discussion in this chapter. I have also made reference to historical origins in order to understand current stances of the DPA.

The six people who have held the position of National President of the DPA since 1983 are introduced in chapter six. It is divided into two parts – in Part A brief biographies of each of them are presented, including an overview of their educational and employment backgrounds and their contributions to the wider disability community. This provides the opportunity to acknowledge their individual contributions and achievements, and to gain some insight into what motivated them to take on the role of president. In Part B I discuss each of their leadership styles, drawing on their (or their spouses/parents) reflections on their leadership style as discussed in their individual interviews. A brief overview of leadership styles is given as outlined by Burton and Dimbleby (1995) and Bass (cited in Bartol, Martin, & Tein, 1998). While it could be argued that the distinctions between these leadership styles are artificial and simplistic, such a model provides a useful tool for analysing the approaches these six individuals took in their role as national leaders of the DPA, and their influence on the direction of the organisation.

Chapter seven addresses some of the significant issues and debates that the DPA has had to confront (and some it's still to resolve). Some material on social movements is outlined and related to a discussion on the disability movement. I then analyse the development of the DPA using a model on organisational life cycles. As part of this discussion some key projects the DPA had initiated are outlined. These projects had considerable impact on the lives of many disabled people and the wider disability

community. The organisational life cycle model outlines challenges for leaders at each stage. I examine how the individual leadership styles of each of the National Presidents since 1983 has contributed in determining the way the organisation faced the associated challenges.

In chapter eight I review the key themes of my thesis. An overarching theme focuses on the DPA as providing the formal organisational focus for the disability movement in New Zealand, especially during the 1980s and early 1990s. However, my analysis of the development of the DPA suggests that from 1993 onwards the DPA focus has been more on the development and maintenance of its infrastructure in order for the organisation to survive, resulting in the DPA becoming removed from the wider disability movement. I argue that the challenge for the leadership in 2000 and beyond is to identify issues for the disability movement and to determine what its continued role within the movement will be, while still developing and maintaining its own organisational structures.

Another key theme reviewed in this chapter is the power of language and disability. In discussing the DPA's organisational structure, philosophies and values I argue that it is essential that the DPA be clear on how disability is defined. I distinguish between the terms 'people with disabilities' (implying that the disability is an appendage only) and 'disabled people' (reflecting that disability is an integral part of the self). The definition and analysis of disability used within the DPA will impact on the composition of its membership, identifying clearly the power base within the organisation and determining the role of non-disabled people and service provider organisations within its structures. Finally, I examine some of the main issues facing disabled people as discussed by the participants in my research and discuss what directions they believe the DPA needs to take, including its ongoing involvement at the international level.

Chapter nine presents an overview of conclusions and recommendations from my research. Key issues that impact directly on the rights of disabled people are reviewed and recommendations made that focus on possible strategies for the DPA to take a leading role in addressing these issues. Significant issues facing the DPA as an organisation are also highlighted. These relate to the DPA's philosophy, structure and composition of its membership and need to be resolved if the organisation is not only to survive, but also to grow.

I see this thesis as being a beginning in outlining significant contributions and achievements by disabled people in New Zealand. This provides the background to examine key issues facing disabled people as we move into the next century, as well as issues that I believe the DPA needs to confront if the organisation is to have a future. By setting an analysis of the development of the DPA and a discussion of issues within a theoretical framework it is my intention to promote discussion and debate around possible future directions for political and social action within the DPA and the wider disability community in New Zealand.

## Chapter 2

### *Disability in Society: A Theoretical Discussion of Frameworks*

#### **Theoretical influences**

Michel Foucault's post-structuralist work on truth, power and knowledge and Michael Oliver's materialist Social Oppression Theory focus on the importance of unpacking discourses surrounding marginalised groups such as disabled people, identifying how the conditions that dictate their lives are socially constructed, and not part of a natural order. Before outlining Foucault's ideas it is important first to outline key concepts of Social Construction Theory.

#### **Social Construction Theory**

Gergen (1985), a social psychologist, explains how social constructionist inquiry is principally concerned with identifying the processes by which people come to describe, explain or otherwise account for the world (including themselves) in which they live. Constructionism challenges what is seen as being objective knowledge and truth as being the result of a particular perspective, that is, knowledge and truth are created, not discovered. Within this framework there is a particular emphasis on the pluralistic character of reality, in that reality is expressible in a variety of symbol and language systems. In place of a positivist view of theories and knowledge, constructionists emphasise the instrumental and practical function of theory construction and knowing.

Constructionists are antiessentialists, assuming that what many take to be self-evident kinds (eg. man, woman, truth, self) are actually the product of complicated discursive practices. Diana Fuss explains that

... what is at stake for the constructionist are systems of representations, social and material practices, laws of discourses, and ideological effects. In short, constructionists are concerned above all with the *production* and *organisation* of differences, and they therefore reject the idea that any essential or natural givens precede the process of social determination (cited in Schwandt, 1994:125).

Gergen states that the social constructionist approach is based on the assumption that

the terms by which the world is understood are social artefacts, products of historically situated interchanges among people (1985:267).

He explains that the process of understanding is not automatically driven by the forces of nature, but rather, is the result of an active, cooperative enterprise of people in relationships. The emphasis is on the collective generation of meaning as shaped by conventions of language and other social processes. Inquiry is therefore focused on the historical and cultural bases of various forms of world construction.

There have been criticisms aimed at the constructionist orientation that it is built on 'rampant relativism'. However, as Gergen (1985) points out

... the attempts to justify objective foundations for knowledge have yet to furnish reason for optimism. One might well argue that the scientist's claims to privileged knowledge has served as mystifying devices within the society more generally. Constructionism offers no foundational rules of warrant and in this sense is relativistic. However, this does not mean that 'anything goes'. Because of the inherent dependency of knowledge systems on communities of shared intelligibility, scientific activity will always be governed in large measure by normative rules... constructivism does invite the practitioners to view these rules as historically and culturally situated... (Gergen, 1985:273).

This brief overview of Social Construction Theory serves to provide an introduction for understanding two theoretical frameworks I will be drawing on in my analysis of the development of the Disabled Persons Assembly as part of a wider disability movement in New Zealand.

## **Post-Structuralism: Truth, Power and Knowledge**

Post-structuralism, and more specifically, Michel Foucault's analyses of power relationships and knowledge offers concepts and ideas which I believe can help to further extend an analysis of disabled people in society.

A structuralist approach attempts to dispense with both meaning and the subject by finding objective laws which govern all human activity, such as in the pursuit of positivist scientific knowledge. An example of this approach being used is the medical model where disability is defined in terms of individual pathology as defined by the medical profession. A post-structuralist approach however works from the basis that

subjects create their own meanings based on their lived experiences and relations with others in society, and therefore, that there are multiple ‘truths’. For example, while the medical model defines disability in terms of individual pathology, many disabled people are sharing their lived experiences and challenging the accepted ‘truth’ as it is presented in the dominant discourses, and thereby defining their own truths about disability. Within this framework, as with social construction theories, Foucault’s ideas lead to pluralism, but not pluralism in which anything goes, but rather, a pluralism that says everything is open to interpretation. It is important to examine the ways in which groups can use concepts of truth, power and knowledge to create a dominant position for themselves and at the same time negate the presence and experiences of other groups. By developing an understanding of these concepts and how they can be used we can begin to identify strategies to change power relations in society.

### **Truth**

Foucault (1926 - 1984) was a French philosopher. As a post-structuralist he rejects the notion of searching for a universal truth, instead “seeing meaning as fragmented, multiple and diffuse” (Pitt, 1998:2). Foucault defines truth as “the ensemble of rules according to which the true and the false are separated and specific effects of power attached to the true” (Foucault, 1984:74). He argues that in our society the relationship between power, right and truth is organised in a highly specific fashion, and that we are forced to produce the truth of power that our society demands. Foucault does not see truth as having originated from objective scientific observation, but rather, as being created from dominant discourses operating within society at that particular time.

Foucault sees that in many analyses of power (domination) that power and truth are seen as being separate - with the assumption being made that once a truth has been spoken, a power (dominance) will be broken (Dreyfus & Rabinow, 1982). He argues that truth and power are not external to each other, rather, that power masks itself by producing a discourse, seemingly opposed to it but really part of a larger deployment of modern power. Foucault further argues that modern power is made more tolerable if it masks itself through the use of ‘truth’ and ‘discourses’.

Foucault identifies discourse as a form of power that he sees can be used in strategies of both domination and resistance. He explains how

in any society there are manifold relations of power which permeate, characterise and constitute the social body, and these relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse. There can be no possible exercise of power without a certain economy of discourses of truth which operates through and on the basis of this association (Foucault, 1980:83).

Munford and Sullivan (1997) argue that discourse functions to regulate the way individuals think about the world and their lives. Lived practices are in turn regulated through ideas, language, institutional behaviour, rituals and social relations. They further argue that within a discourse power operates insidiously and unconsciously as a particular view is presented as 'truth' and beyond question.

According to Foucault, the essential political problem is to ascertain the possibility of constituting a new politics of truth. He argues that it is not about changing people's consciousness - but rather about changing the political, economic, and institutional regime of the production of truth. Therefore, it's a matter of detaching the power of truth from the hegemony - social, economic, and cultural - within which it operates at the present time (Foucault, 1980).

### ***Power***

A central focus for Foucault and other post-structuralists is on how subjects are constituted by power relations at any point in time. Just as he rejects the notion of 'universal truth', Foucault also challenges the notion of having a 'grand theory' to understand power structures in society. He argues that although global theories have provided (and continue to provide) useful tools for research:

These tools have only been provided on the condition that the theoretical unity of discourses was in some sense put in abeyance... that the attempt to think in terms of a totality has in fact proved a hindrance to research (Foucault, 1980:81).

Foucault says that the role of theory is not to formulate the global systemic theory that holds everything, but instead to analyse the specific mechanisms of power, to locate the connections and extensions, to build a strategic knowledge. He argues that theory should be seen as a toolkit so that (i) the theory to be constructed is not a system but an instrument, a logic of the specificity of power relations and the struggles around them;

and (ii) that this investigation can only be carried out step by step on the basis of reflection (which will necessarily be historical in some of its aspects) on given situations (Foucault, 1980:145).

Sawicki, (1991:21) outlines Foucault's critique of global theories which he sees are based on the following assumptions:

1. That power is possessed (ie. by individuals in the state of nature, by a class)
2. That power flows from a centralised source from top to bottom (ie. the law, the economy, the State)
3. That power is primarily repressive in its exercise (ie. a prohibition backed by sanctions).

Foucault argues that power is exercised and only exists in action (and therefore is not a commodity that can be owned or exchanged), and that power is not primarily about the maintenance and reproduction of economic relations - rather, it is a relation of force (Foucault, 1980). He argues that power needs to be analysed in terms of a struggle or a conflict that occur at both the minute, local levels of peoples lives as well as at the global levels. While recognising that the State is important when looking at power, Foucault argues that what is more important is to analyse the relations of power. He points out that while the State's powers are far reaching, it is far from being able to occupy the whole field of actual power relations. The State can only operate on the basis of the other, already existing power relations (Foucault, 1984). Further, he argues that nothing in society will be changed if the mechanisms of power that function outside, below and alongside the State apparatuses, on a much more minute and everyday level, are not also changed (Foucault, 1980).

According to Foucault then, power is the name that one attributes to complex strategic relationships in a particular society and must be analysed as something which circulates and which only functions in the form of a chain. He sees that power is employed and exercised through a net-like organisation, and that not only do individuals circulate between its threads, they are always in the position of simultaneously undergoing and exercising this power. Therefore Foucault argues that individuals are not only passive or consenting targets of power; but they are always also the elements of its articulation. Hence individuals are both the vehicles of power and its point for application.

In order to understand power Foucault states that we should not attempt some kind of deduction of power whereby

starting from its centre and aimed at the discovery of the extent to which it permeates into the base, of the degree to which it reproduces itself down and to including the most molecular elements of society (Foucault, 1980:98, 99).

Instead, Foucault says we need to conduct an ascending analysis of power.

Starting from its own small mechanisms (with their own history, techniques and tactics) and see how these mechanisms have been invested, colonised, utilised, transformed... displaced, and extended by ever more general mechanisms and by forms of global domination (Foucault, 1980:99).

This approach will have relevance in the analysis of data in this thesis as respondents reflect on the impact of power relations experienced in their own lives as disabled people and of other disabled people, as well as their analyses of power relations in the wider policy and political arenas.

Foucault has problems with seeing power as being repressive.

In defining the effects of power as repression, one adopts a purely juridical (liberal) conception of power, one identifies power with a law which says no; power is taken above all as carrying the force of a prohibition. Now I believe that this is a wholly negative, narrow, skeletal conception of power... If power was never anything but repressive... do you really think one would be brought to obey it? What makes power hold good... it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body... (Foucault, 1984:60, 61).

For Foucault, as power is exercised and not simply held, it is about the operation of the political technologies throughout the social body. Foucault emphasises the body as the place in which the most minute and local social practices are linked up with the large-scale organisation of power. Relations of power are therefore interwoven with other kinds of relations such as those involved with production, kinship, family, and sexuality and they play both a conditioning and a conditional role. There is thus a tendency for

power to be depersonalised, diffused, relational, and anonymous, while at the same time totalising more and more dimensions of social life (Dreyfus & Rabinow 1982:192).

Liggett (1997:190) points out that Foucault's concept of the "body as a battlefield" says something about how intimately disabled people are involved in conventional social practices. She argues that because of this intimate nature, the struggle will be particularly arduous and subversive for disabled people. This can be seen in the struggles that many disabled people have in accessing appropriate services to have their basic daily needs met. They are subjected to intrusive assessment processes (Munford, 1990) with no guarantees that services will be provided. A failure to have appropriate services provided can have significant and often disastrous consequences on the disabled person and their family.

Foucault concentrates on micro-powers that are exercised at the level of daily life, arguing that tactics of power were invented and organised from the starting points of local conditions and particular needs (Foucault, 1980). If power is no longer seen as coming from a centralised source, the practical implication is that resistance must be played out at the local level, in struggles against the many forms of power exercised at the everyday level of social relations (Sawicki, 1991). This approach is encouraged in the structure of the DPA (see Chapter five) which allows for regional assemblies to operate to organise social action on local issues. Foucault argues that where there is power there is resistance, and in fact, power is dependent upon resistance.

### ***Knowledge***

Foucault views history as the play of rituals of power, with humanity advancing from one domination to another (Dreyfus & Rabinow, 1982). Questions relating to how we know and what kinds of knowledge become institutionalised in established practices become of interest to political theorists because knowledge, and the constitution of available identities, is connected to the operation of power in society. Interpretations do not exist separately from the practices of social life, rather, are embedded in systems of meaning which are our social life (Liggett, 1997). History can therefore be represented as 'truth', drawing on the knowledge and experiences, discourses and interpretations of dominant groups, while subjugating or burying the knowledge and experiences of other groups. This subjugation of some knowledges impacts on current discourses surrounding such groups and it is therefore necessary to provide resistance to this domination in order for conditions at both the local and State levels to change.

Resistance can occur at the micro level in terms of challenging what is done to people and at the macro level in terms of challenging structures. Foucault identifies two ways in which resistance can be developed - resistant subjectivity and genealogy as resistance. Resistant subjectivity opens the way for a different understanding of historical knowledge of struggles, bringing out forms of knowledge and experience that have tended to be ignored, such as those from psychiatric patients and prisoners. Such knowledges are known as subjugated knowledges and are

a whole set of knowledges that have been disqualified as inadequate in their task or insufficiently elaborated...[They are] knowledges located low down on the hierarchy, beneath the required level of...scientificity (Foucault, cited in Munford & Sullivan, 1997:17).

However, as these knowledges emerge they provide oppositional perspectives that challenge taken-for-granted ways of knowing the world.

Linked to this is the concept of genealogy of resistance, which involves giving voice to the history of the marginalised - that is, encouraging people to tell their stories. According to the analysis of power and resistance, freedom lies in our capacity to discover the historical links between modes of self-understanding and modes of domination and to resist the ways we have been classified and identified by dominant discourses. For example,

a detailed genealogy of disability would investigate how various shifting social practices constitute and administer disability in the normalising society, showing exact instances of struggle and transformation (Liggett, 1997:190).

One means of both providing resistance to dominant knowledge and discourses and resurrecting subjugated knowledges is to present criticisms at local levels of things that uphold the dominant regimes in a society.

Foucault states:

I believe that what this essentially local character of criticism indicates in reality is an autonomous, non-centralised kind of theoretical production, one that is to say whose validity is not dependent on the approval of the established regimes of thought (Foucault, 1980:80).

This local criticism has resulted in what he terms “a return of knowledge”. He argues that in recent times there has been an entire thematic to the effect that it is not theory but life that matters, not knowledge but reality, that

Over and above, and arising out of this thematic, there is something else to which we are witness... an insurrection of subjugated knowledges (Foucault, 1980:80).

Munford and Sullivan (1997) discuss the notion of resistance in relation to disability. They state that some writers criticise the concept of disabled people as being oppressed, arguing that it encourages disabled people to create themselves as victims (Munford & Sullivan, 1997). They argue that writing from this perspective, power is seen to operate in a unidirectional, top down, unified way on victims; that there is no place for points of resistance.

All in all, a rather bleak place to be... Also, this is an analytical cul-de-sac because where does one go from here? (Munford & Sullivan, 1997:21).

Rather than dismissing the notion out of hand, Munford and Sullivan (1997) argue that it is more productive to see the re-naming of ‘disability’ as social oppression as an example of “moments of resistance”. People then begin to realise that their marginalisation was not natural and inevitable but, rather, is something that was created by humans and can therefore be changed.

Rioux and Bach (1994) discuss how disabled people are creating resistance to the dominant discourses held in Western societies about disability. They argue that the voices of disabled people are being heard in spite of the efforts of non-disabled people. This resistance, they argue, is reflected in the emerging disability culture where disabled people are developing appropriate language and transforming it or inventing new words, metaphors, myths and images that reflect their own images of the world. Rioux and Bach see that this movement started with disabled people developing their own sense of pride and community which comes from having a positive, self-defined group identity. In this thesis I will discuss how in the early stages the DPA was the focal point for disabled people in developing their own sense of pride and community.

However, Liggett (1997) warns that taking on the identity of disabled people as a marginalised group may in fact reinforce the status quo rather than challenging it. She argues that the minority groups approach is double-edged because it means enlarging the discursive practices that participate in the constitution of disability. Liggett suggests

that the price for disabled people becoming politically active on their own behalf is to therefore accept the consequences of defining disability within new perspectives, which have their own priorities and needs. An example of this is where disability groups' strategies operate on the basis of their own kind of distinctions between disabled/non-disabled people, participating in and reinforcing a disciplinary society with the oppositions in the normalising society among normal and various forms of deviance remaining intact (Liggett, 1997). Liggett warns that disability politics need to investigate further how the perpetuation of disabled identities helps ensure that disabled people participate in the normalising society. She reminds us that a central contribution of discursive analysis is that it allows us to look at how language practices work to produce disabled identities. Therefore, I believe that if such an analysis is used in conjunction with resurrecting subjugated knowledges it could provide opportunities for disabled people to challenge those practices that are perpetuated in dominant discourses to work in different ways.

The need to retrieve the subjugated knowledges of disabled people and to unpack language practices in relation to disability are key focuses of this thesis. Within the DPA disabled people are encouraged to share their stories which are used to illustrate gaps in services and systems, and as a means of gathering anecdotal evidence to support arguments for changes in current policies. The use of stories can also enable disabled people to identify common themes as they develop an awareness and begin to recognise that the difficulties and disadvantages they encounter are not wholly attributable to their personal 'deficits'. The use of knowledge gathered in the research for this thesis will challenge dominant images of disabled people as passive players in power relations.

### ***Social Oppression Theory of Disability***

A theory that has had a significant influence in the development of my analysis of disability in society is Social Oppression Theory, which comes from a materialist base. This theory has many areas of overlap with post-structuralism as the focus of its proponents is to deconstruct dominant discourses and the language surrounding disability, and to challenge the marginalised position of disabled people in society. The underlying principles of this theory originated from a document *Fundamental Principles of Disability* published by UPIAS<sup>1</sup> in 1976 and later expanded by Michael Oliver in his

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<sup>1</sup>UPIAS is the Union of the Physically Impaired Against Segregation formed in Britain in 1972.

book *The Politics of Disablement* (1990). Oliver is a disabled person himself who has been involved in social action and is committed to bringing about social change for disabled people (Campbell & Oliver, 1996). His stated intention was to place disability onto the political and academic agendas, to develop a social theory of disability based on the lived experiences of disabled people.

Oliver argues that the way disability is defined is crucial.

The social world differs from the natural world in (at least) one fundamental respect; that is, human beings give meanings to objects in the social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them (Oliver, 1990:2).

In society disability is predominantly seen as being a medical 'problem' (Georgeson, 1989; Oliver, 1990, 1996; Morris, 1991; Sullivan, 1991; Campbell & Oliver, 1996; Munford & Sullivan, 1997). Viewing disability from within the medical model individualises people's needs, states and concerns. 'Disability' is seen as a 'condition' that requires 'treatment'. The onset of a disability (including the birth of an impaired child) is seen as being a personal tragedy which individuals need help to work through in order to come to terms with. Oliver argues that if disability is defined as a personal tragedy then disabled people will be treated as victims in everyday interactions, and this will be translated into social policy. Campbell and Oliver (1996) discuss how the medical model has impacted on the self-identity of disabled people, with people they interviewed reflecting on how they saw themselves as being ill, and how they found themselves living in institutions where structures were established that dictated what individuals were able to do.

There is a growing movement, of which DPA identifies itself as being a part, which is providing resistance against the dominance of the medical model of disability. Oliver (1990) and Sullivan (1991) offer critiques of the medical model's view of disability. Oliver criticises the definitions presented by the World Health Organisation that maintains the notion of impairment as the abnormality in function, disability as not being able to do an activity considered normal for a human being, and handicap as the inability to perform a normal social role. These definitions ignore the issue of what normality actually is, and fail to recognise the situational and cultural relativity of 'normality'. Oliver argues that the WHO's definitions take the environment for granted even though the handicap is no longer considered to be within the individual. As long

as the environment consists of social roles that are considered to be normal, the inability of the individual to live up to the requirements of these roles puts them in a disadvantaged position and therefore creates a handicap. This definition, Oliver argues, maintains the medical model approach since changes must be brought to bear on the individual rather than the environment. He states that while the WHO definition recognises that disability has both individual and social dimensions, it does not see disability as arising from social causes. Therefore, Oliver argues, ultimately their rationale appears to rest on the social dimensions of disability and handicap arising as a direct consequence of individual impairments.

Oliver offers an alternative definition of 'impairment' and 'disability'.

*Impairment* - lacking part or all of a limb, or having a defective limb, organism or mechanism of the body;

*Disability* - 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 the mainstream of social activities (1990:11).

This definition shifts the cause of disability away from individual pathology, locating it instead within society and social organisations as Munford explains.

In a social model of disability the principal cause of disability is situated in restrictive environments and disabling barriers wherein disability represents a complex system of social constraints imposed upon people by a highly discriminatory society (Munford, 1994:6).

A crucial element in redefining disability is the terminology used. Throughout the DPA's constitution, promotional material and policy documents reference is made to 'people with disabilities'. Oliver (1990) argues that 'people with disabilities' reflects that the disability is an appendage only, whereas the term 'disabled people' reflects that disability is an integral part of the self. Sullivan (1991) also explicitly refers to disabled people rather than people with disabilities, vehemently arguing that the term 'people with disabilities' (seeing the person first and the disability second) is a nonsense. He argues that it is predominantly non-disabled professionals and some disabled people that have adopted the sanitised 'people with disabilities', and that the term denies the identity and experiences of disabled people. The membership of DPA is made up of

disabled people and non-disabled people, including professionals working in the disability sector, which might explain how the 'people with disabilities' has such widespread acceptance within DPA and the wider disability community in New Zealand.

I also find it difficult to talk about the person and the disability separately and agree with Oliver (1990) that we must be accepted as we are, as disabled people. Therefore, throughout this thesis I will use the term 'disabled people' unless I am quoting from the DPA's material or other sources that use the term 'people with disabilities'.

Oliver (1990, 1992) argues that the way the experience of disability is structured will be different in each society, outlining how, for example, in Western industrialised societies the rise of capitalism and the development of industrialisation meant that certain groups of people were no longer able to work. He discusses how systems were developed to determine who were 'unable' and who were 'unwilling' to work and that with widespread poverty came the need to distinguish between the 'deserving' and 'undeserving' poor in order to determine who should get aid. Thus, Oliver argues, certain groups of people were identified as being 'disabled', and therefore deserving of charity, and later 'welfare aid'. He goes on to describe how the medical profession contributed significantly in this classification process, eventually determining that disabled people needed to be moved away for their own protection, preferably into institutions, as they were unable to function in society. This, he argues, further increased the power of medical professionals, with the emphasis being on the need for disabled people to have specialised interventions and programmes which could not be provided for in community settings. Nowhere in the medical model approach is there the recognition that maybe societal structures need to change in order to meet a wider range of people's needs!

Oliver (1996) places disability clearly in the political arena, identifying circumstances that disabled people and their organisations face as being a direct consequence of the political economy in which they operate. In his view the political economy is the crucial, ultimately determining factor, in structuring the lives of groups and individuals. He states that while the relationships between various groups may differ in qualitative ways, the underlying structural relationship remains. Oliver goes on, quoting Walton:

... racism, sexism, ageism and economic imperialism are all oppressive 'isms' and built-in responses of a society that considers certain groups inferior. All are rooted in

the social-economic structures of society. All deprive certain groups of status, the right to control their own lives and destinies with the end result of powerlessness. All have resulted in economic and social discrimination. All rob society of the energies and involvement of creative persons who are needed to make our society just and humane. All have brought on individual alienation, despair, hostility and anomie (1996:133).

It can be argued that disability and the experiences of disabled people have been largely ignored by mainstream theories. Oliver (1990) states that a social theory of disability must be integrated into existing social theories and must be located within the experience of disabled people themselves and their attempts to not only redefine disability, but also to construct a political movement amongst themselves. The emergence of the disability movement is an example of how disabled people have begun to construct such a political movement.

### **The Disability Movement as a Social Movement**

Abberley (1997) discusses Touraine's theory of social movements and relates this to the disability movement in Britain. He begins his discussion by examining how theoretical frameworks such as Marxism and feminism involve the notion of working towards a utopia in which freedom might be achieved. He illustrates this, suggesting how within a Marxist framework the goal might be to strive for full integration in the world of work for impaired people. However, he argues:

For impaired people the overcoming of disablement whilst immensely liberative would still leave an uneradicated residue of disadvantage in relation to power over the material world. This in turn restricts our ability to be fully integrated into the world of work in any public society... (Abberley, 1997:38).

He continues, arguing that:

A liberative theory of disability requires the posing of values counter to the classical sociological and revolutionary consensus, **the assertion of the rights of the human being against the universalisation of the human 'doing'** (Abberley, 1997:38) (Emphasis added).

Abberley explains that Touraine's definition of a social movement emphasises how a social movement poses challenges to prevalent belief systems. For Touraine the aim of

a social movement is not simply to react against existing inequalities, but rather to try to change the norms and values of cultural and social life. This is an important feature that helps to distinguish between a social movement and a class struggle.

The idea of a social movement... is radically different to the idea of class struggle. The latter appeals to the logic of history, whereas the former appeals to the freedom of the Subject, even if that means rejecting the pseudo-laws of history... we must open up individual and collective clearings in the forest of technologies, rules and consumer goods. The demise of the political programmes and apparatuses that had dominated the last hundred years is opening up an already crowded space for ethical principles and truly social movements (Touraine, in Abberley, 1997:40).

According to Abberley, social movements such as the disability movement are not just reacting to marginalisation. They are actively involved in consciousness-raising within their membership and in the wider society, as well as exploring and promoting different cultural values and norms in relation to disability than are evident in current dominant discourses. In New Zealand, evidence of this process beginning in a coordinated way can be seen in activities organised as part of the IYDP in 1981 when disabled people, disability consumer groups and service providers worked together to raise public awareness of disability issues. This provided a platform for disabled people to begin telling their stories to each other and the wider community, debunking the dominant discourse that sees disability as an individual deficit. As a result, they began to challenge their marginalised position in society, with demands being made for physical, structural and attitudinal barriers to be addressed in order for disabled people to be recognised as citizens with rights.

Oliver and Zarb (1997) argue that as social movements are developed from a marginalised position people are engaged in consciousness raising activities such as demonstrations and other political activities. In this way groups within the disability movement can develop links with other marginalised groups (including developing links between impairment groups) so that their potential as a whole is greater than that of their constituent parts.

It can be argued that the establishment of the DPA (as outlined in chapters four and five) provided both a focal point and an organisational structure for the disability movement in New Zealand. Therefore, a discussion on the role of the DPA in the

emergence of the disability movement needs to include an analysis of the development of the DPA as an organisation.

## **Organisational Life Cycles**

In addition to the theories outlined here which I am using to provide a framework from which to develop an interpretation and analysis of the development of the DPA, it is also important to examine its development using organisational theory. The examination of the life cycle of an organisation contributes to an understanding of the different phases of the DPA during its development and the challenges the leadership negotiated. Although this model was developed as a tool to understand business organisations I believe it can also be applied to non-profit making organisations. An analysis of leadership styles within the DPA is included as part of this discussion as the approaches of the leaders have had a significant influence on the direction of the organisation.

Bartol, Martin, Tein, Matthews (1998) argue that there are predictable stages of development that organisations pass through and that progress through each stage requires specific changes by the organisation in order for it to survive and grow. They identify four stages:

- Entrepreneurial stage
- Collectivity stage
- Formalisation and control stage
- Elaboration-of-structure stage

In their discussion Bartol, Martin, Tein, & Matthews (1998) make reference to how an organisation follows similar steps to those in human development. The entrepreneurial stage for an organisation (equated with the infancy stage) is a time for naïve optimism and marked as a time for rapid growth. At the collectivity stage the organisation is in its youth, with members connecting strongly with shared goals and ideals as they work to develop organisational structures and systems. An organisation has reached adulthood at the formalisation and control stage with the emphasis on achieving efficiency, and the control of decisions and the operations of the organisation become centralised. The Elaboration-of-structure stage is the final stage. It is identified that many organisations become overly bureaucratic and inefficient and therefore the focus at this stage is on

revitalisation, with a renewed emphasis on innovation and the development and implementation of strategic directions.

This model is useful as it highlights organisational issues that need to be addressed and the type of leadership approach that is effective at each stage. Devito (1997) and Bass (cited in Bartol, Martin, Tein & Matthews, 1998) outline frameworks of leadership styles that outline dominant traits and preferred ways of working. Devito identifies three main leadership styles – the laissez-faire leader, the autocratic leader and the democratic leader. Bass distinguishes between transformational leaders and transactional leaders and discusses ideal situations for each leadership approach. Using these models in conjunction with each other is helpful in the analysis of the development of the DPA as an organisation and helps to identify strategies required to ensure the DPA's survival and growth.

## **Conclusion**

Disabled people in New Zealand and other Western societies are involved in power struggles where dominant structures, knowledges and discourses emphasise the needs and the achievements of non-disabled people. This chapter gives a brief overview of Social Construction Theory, key concepts and ideas from Michel Foucault's work on truth, power and knowledge, Social Oppression Theory as developed by Michael Oliver and his colleagues, and Abberley's analysis of the disability movement based on Touraine's theory of Social Movements. These theoretical frameworks focus on the importance of unpacking discourses surrounding marginalised groups such as disabled people and identifying how the conditions that dictate their lives are socially constructed, and not part of a natural order. Foucault and Oliver emphasise the importance of gathering stories of the lived experiences of marginalised people and incorporating these in order to challenge existing relations of dominance in society. Abberley also focuses on the marginalisation of disabled people, but stresses that the disability movement is not just a reaction to marginalisation. He argues that the disability movement is actively involved in consciousness-raising among disabled people, and in the exploration and promotion of different cultural values and norms in relation to disability than are evident in current dominant discourses.

Foucault's analysis of power is particularly useful in extending our understanding of the position of disabled people in our society. As power is seen as being actively exercised

in relations throughout the social body Foucault argues that the body is the place from where the most minute and local social practices are linked with the large-scale organisation of power. As power is exercised there are opportunities for resistance to be organised. This notion of resistance presents a framework for developing strategies for disabled people to work together to challenge the dominant models in relation to disability. However, it is important to take cognisance of Liggett's warnings that to take on the identity of disabled people as a marginalised group may in fact reinforce the status quo rather than challenging it. Strategies for change therefore need to include the deconstruction of language practices to look at how disabled identities are produced, and how alternative images can be created.

These theoretical frameworks offer a firm base from which to interpret the individual stories and recollections from the DPA presidents from 1983 to the present. I use these recollections to examine the power relations (of which disabled people are involved), to highlight their struggles, and to identify points where resistance has occurred. By working through this process it is possible to identify strategies that can be used in the future by disabled people to bring about meaningful and lasting social and structural changes at the micro and macro levels of society.

Finally, by using a model drawn from organisational theory I can examine the phases the DPA has gone through since its inception in 1983. This model, which outlines organisational life cycle stages, helps to understand the challenges for organisations at various stages of its development. I believe it is a useful tool to analyse how the DPA and its leadership has responded to the challenges and adapted at each stage, and I believe, provides some signposts for the DPA in its planning for future directions.

## Chapter 3

### *Methodology and Methods*

#### **Methodology**

This research draws on an interpretivist methodology that is described and discussed in relation to the research topic throughout this chapter. In particular, the place of topical life histories is considered. Specific research procedures are recorded, the research sample is introduced and the interviewing processes are recorded and discussed.

Methodology in social research refers to the underlying theoretical and philosophical viewpoints that guide the research process.

Michael Oliver argues that

the social relations of research production provides the structure under which research is undertaken (Oliver, 1992:102).

He argues that industrial societies have produced disability first as a medical problem requiring medical intervention and second as a social problem requiring social provision. Research has largely operated within these frameworks and tried to classify, clarify, map and measure their dimensions. Research has tended not to tell the stories of disabled people, to identify sources of their oppression, or to challenge structures. The “social relations of research production” make a distinction between the ‘researcher’ and the ‘researched’ where the researchers are ‘experts’, and only they can decide what topics can be researched and therefore control the research process. Oliver strongly challenges this, arguing that disability research should not be seen as a set of technical, objective procedures carried out by experts, but rather should be used by disabled people to challenge the oppression currently experienced in their daily lives. Oliver challenges researchers, asking if they are going to work alongside disabled people and be part of the solution, using their skills and expertise in the struggle against oppression, or are they going to continue using their skills in ways that disabled people find oppressive. Such challenges have influenced the approach I used in the design of my research.

Two dominant paradigms have been used in social research, the positivist paradigm and the interpretivist paradigm (Oliver, 1992; Smith, Noble-Spruell, 1986). Within the positivist paradigm the following assumptions are held:

- That the social world can be studied in the same way as the natural world
- That the study of the social world can be value free
- That explanations of a causal nature can be provided
- That knowledge obtained from social research is independent of the assumption underpinning it and the methods used to obtain it.

These assumptions have been challenged over the years. Generally now it is recognised that knowledge is socially constructed and is a product of the particular historical context within which it is located. This shift has led to the development of the interpretivist paradigm with the following assumptions:

- That there can be no one method for the social world is a meaningful place, full of active subjects not passive objects
- That research should attempt to understand the meaning of events as well as their causes, and
- That research is a product of the values of researchers and cannot be independent of them.

Within interpretivist methodology there is a concern therefore to understand the world from the point of view of the individuals and groups who are participants in the research. Adherents of interpretivist methodology are more likely to have a preference for qualitative research techniques, including the unstructured or semi-structured interview that uses open-ended questions to allow respondents to express their ideas and experiences more fully. Using this approach, data is more likely to be reported through direct quotations from the participants.

In this project I wanted to gain an understanding of the development of the DPA from the perspective of individuals who had been involved at different times during its history. I therefore selected the individuals to be interviewed as it was important to have participants who had a clear understanding of the beginnings of DPA and the issues they were confronting at that time. The participants in this project were able to

articulate the issues and provided a range of perspectives and interpretations of the development of the DPA.

My research design was based on the interpretivist paradigm. Qualitative research techniques were used, namely, a semi-structured interview schedule from which a range of topics were explored relating to the developing philosophy of DPA, achievements made through DPA, its leadership, and future directions; and reviewed relevant documents (in this case, minutes, policy documents and other publications from DPA). The semi-structured interview schedule enabled the respondents to express their ideas and experiences fully. Spicker (1995) states that qualitative research is commonly aimed at producing material to help explain issues, answering questions beginning with 'why?', 'who?', 'how?', as well as some questions about process - like 'what is happening?'. This thesis looks at questions such as who were the key players in establishing the DPA, and what was their primary motivation? Philosophies and values of the organisation and the key issues that faced disabled people and impacted on the DPA at different times during its history are also explored, as well as current issues.

### ***Topical Life History as a Qualitative Research Technique***

I decided life history methods offered a range of techniques that could help in tracing the development of the DPA as an organisation. It is also a useful method for bringing together profiles of some key people who have been involved in DPA, to recognise their achievements both as individuals and collectively.

The life history approach is seen as being a method which enables researchers to not only develop an overview of individuals' lives, but also to be able to relate those experiences within the social context of that time.

Since its beginnings, the biographical method has been tied to theoretical approaches emphasising the importance of subjectivity in social processes (Szczepanski cited in Kohli, 1981:63).

And Denzin tells us that

the life history presents the experiences and definitions held by one person, one group, or one organisation as this person, group, or organisation interprets those experiences (Denzin, 1970:220).

As this definition implies, the purpose of life histories is to not only present an overview of a person's life, but also to place the subject's experiences within the wider social context, that is, looking at what the conditions were in that particular point in time. The role of the researcher is then to use this material to begin to identify some trends, although there is debate as to how much interpretation the researcher should try to impose on the material gathered.

Rees (1991) explains that 'biography' (life histories) is a process of depicting the life of a group of individuals with something in common or the activities of an organisation over time. He discusses how the unravelling of biography requires the bringing together of past and present events and making projections about the future. The promise of biography, he argues, is in the telling of a story with a view to participating in a different way in future events. It also shows the association between personal and political identity through a process of change, from feeling unworthy or incapable, to exerting a measure of choice and control. The biography process focuses on the struggle to make sense of individual circumstances in relation to the dominant constraints and opportunities of a specific issue and time. It is an acknowledgment of the continuous and ongoing process of trying to comprehend and influence the world around one and is about the growth of freedom and the exercising of power in a spontaneous and creative way (Rees, 1991).

Foucault (in Sawicki, 1991) emphasises the importance of having people tell their own stories, a technique which Foucault argues gives a voice to marginalised people. He states that the use of biographies can help in the process of locating discontinuous and regional struggles against power both in the past and present. This will be significant in analysing the DPA's development, as a crucial part of its organisational structure is its regionalised activities that it relies on to feed back issues to the national level.

Allport (in Denzin, 1970) identifies three main forms of life history writing. These three forms are the comprehensive, the topical, and the edited. Factors that distinguish between these forms is whether the focus of the life history is to try and get a picture of the subject's total life, or to present a picture of a particular topic. The complete life history attempts to cover the entire view of the individual's life experiences to that point (Denzin, 1970) whereas the topical life history focuses on only one phase of the subject's life (as in this project, the participants involvement with the DPA). The edited life history may be either topical or complete with its key feature being the continual

interspersing of comments, explanations, and questions by someone other than the focal subject.

Many documents can be used in developing life histories including diaries, letters, fictional texts, official records, and newspaper and magazine articles. Denzin (1970) discusses how public archival records (eg. official records, newspapers) can help to build a picture of the area the subject lived in (statistics); political decisions made at that time, and the reactions to them; as well as referencing particular events. The use of archival records is very important as part of the triangulation process in which other sources of information are used to verify the subject's story. In my thesis they serve to verify, or to examine contradictions in recollections people had of the development of the DPA. The National Office of DPA in Wellington had archival records from when DPA first started. These records include back copies of the DPA publications (DPA Bites and Able Update), Annual Reports and other material from National Conferences and Annual General Meetings. I was given complete support from the national Secretariat of the DPA, having been granted full access to their archival material.

Since the 1930s there has been debate as to whether the life history can be seen as a 'real' form of research, as it is argued, this research cannot generate theory, and hypotheses cannot be tested (Denzin, 1970). It has been argued that it is difficult to accept the outcomes of research using life histories because it is perceived not to be objective. However Denzin (1970) argues that life histories lend themselves to processes of analytical induction. Such processes involve the researcher starting from observed data (the subject's recollection and perspective of events that occurred in their life) and developing a generalisation which explains the relationships between the objects (phenomena) being observed, that is, moving from concrete observations to develop a general theoretical explanation. Denzin explains how

the thrust of analytic induction... is to formulate, through progressive revisions of the research hypothesis, a series of propositions that have universal application. The life history method becomes the paradigmatic form of the analysis, for the investigator *assumes* that the case, or cases, he has intensively analysed portray the universe from which they were selected (1970:238).

Plummer (1983) states that a major tradition of sociology is the importance of studying the ways in which participants of social life construct and make sense of their particular world. He notes how many research methods have been identified with this particular

tradition (the phenomenological approach), for example, participant observation. Within these approaches, the subjective interpretations and reflections from the subjects are fundamental.

Plummer (1983) argues that social sciences are continually trying to impose structured meaning and order onto people's experiences, for example, where questionnaires attempt to get people to structure aspects of their lives into a particular format required. He states that the life history technique is well suited to discovering the confusions, ambiguities and contradictions in everyday experiences. This will have particular relevance in examining the development of the DPA. There were a number of political players involved within the organisation, as well as wider social and political forces that influenced and impacted on the DPA as an organisation and the lives of disabled people and their families who comprise the DPA membership. The life history approach enables us to see the 'total picture' of the subject and provides a valuable tool for history. In this thesis the life history approach allows me to explore the power relations of which disabled people as individual participants and the DPA as an organisation were actively involved.

Despite the enthusiasm expressed by writers such as Plummer (1983), questions are often raised about objectivity within the life history approach. Within this, there are questions related to internal/external validity and reliability. Plummer (1983) explains that reliability is essentially concerned with technique and consistency - that is, ensuring that if someone else conducted the study similar findings would be obtained. Validity on the other hand is concerned with making sure that the technique is actually studying what it is supposed to. He argues that reliability is generally the pre-occupation of 'hard' methodologies, where the focus is on getting the questionnaire questions as replicable as possible through standardisation, measurement and control. Fraser (in Plummer, 1983:120) notes

it is probably safe to say that validity is more likely to decrease as the ease with which reliability is tested increases.

Conversely, he argues that the closer one is to the phenomena one wants to understand, the nearer one is to achieving 'validity'. He explains that

if the subjective story is what the researcher is after, the life history approach becomes the most valid method (Plummer, 1983:102).

He concludes that it is more important for researchers to examine possible sources of bias that might inhibit the life history document from telling the researcher what is wanted, and to employ techniques to reduce the possible sources of bias. The emphasis of this thesis is to gather the subjective stories from individuals who have had significant leadership roles in the DPA as part of a process for developing an understanding of the DPA's story.

### ***Specific Research Procedures Used***

Initially I intended to have two parts to my research project - one giving individual profiles of people who had been involved in the DPA, the other to compare the development of the DPA in New Zealand with the development of the British Council of Organisations of Disabled People (BCODP). The DPA has had an active role in the international disability arena. I thought it would have added an interesting dimension to compare the development of DPA with another comparable organisation, to identify similarities and differences both in the perspective and philosophies of the respective organisations, and of the issues facing disabled people in New Zealand and Britain. I hoped that such a project might begin to explore whether in fact a 'disability movement' was developing, and whether it exists as an international phenomenon. While I still believe that such a project has exciting potential, as the planning for this project became more focused, I realised that to retain the two parts would have made it unmanageable. The main difficulties would have been with funding and having a manageable timeframe, and as this thesis was developed to meet the requirements for a three-paper thesis it is unlikely that I would have been able to do justice to both parts.

I narrowed down the focus of this thesis to researching the development of the DPA and decided to interview the National Presidents (or their surviving spouses) from 1983 to the present, (a discussion on the research sample is in the following section). I developed a research proposal and this formed the basis of an application for funding from the Massey University Graduate Research Fund. I was granted \$1,200, subject to approval from the Massey University Human Ethics Committee.

An application for approval of this project was submitted to the Massey University Human Ethics Committee, Palmerston North. I was not required to address the Committee, but I was asked to submit written evidence from the DPA that they were

supporting my research. Dave Henderson, the Chief Executive Officer, wrote directly to the Committee to indicate DPA's support.

Sections from my research proposal and an explanation of my background and personal interest in the project were sent to Dave Henderson, who was then the Chief Executive Officer of DPA, as part of my formal request for support from the current National Executive Committee. Dave Henderson consulted with Paul Gibson, the National President of the DPA. I was informed via e-mail that the National Executive Committee of the DPA was happy to support my project. The DPA requested I consult with Dave Henderson as he had been involved with the DPA from the beginning and had access to the archival records I needed. The DPA also requested I give Dave Henderson a copy of the penultimate draft of my thesis for his information and comment. I agreed to comply with these requests, however since I started this project Dave Henderson has left the organisation and is now based overseas.

In my initial proposals I had indicated I would facilitate a 'focus group' interview with current members on the National Executive Committee based on the interview schedule for the individual participants. The intention of this focus group was to develop a picture of what the current National Executive Committee see are the issues for the DPA, how they perceive their role in the 1990s, and their perceptions of the development of the DPA. I anticipated that such a discussion could help to clarify any points if required. This did not occur as I decided I had gathered good quality data from the individual interviews and archival records. I maintained regular contact with Dave Henderson and his successor, Gary Williams, and staff in the Secretariat who were able to provide me with the access to adequate documentation I required, as well as providing additional information and clarification as needed.

### ***The Research Sample***

Once I had gained approval from the Massey University Human Ethics Committee, I worked through Dave Henderson to obtain the last known mailing addresses for the people who had been National President of the DPA since 1983.

There have been six people who have held the position of National President of the DPA since its inception in 1983, three of whom have since died. In the situation where a past president has died, I approached their surviving spouse, with the focus was on having them reflect on their partner's time as National President. The participants in

this project were Pauline Angus (wife of the first President, the late Quentin Angus), Lindsay and Mary Buick-Constable (the parents of the late Byron Buick-Constable)<sup>2</sup>, Mary Stott (wife of the late John Stott), Marilyn Baikie, Anne Hawker and the current President, Paul Gibson.

Campbell and Oliver (1996) state that when they selected the people to interview, they did not use random selection, quota, or any other form of sampling, rather they contacted people who they felt would have useful things to say. In this project I was also specific about whom to approach. It was important to interview people who had a clear understanding of the beginnings of DPA and the issues they were confronting at that time. I identified people who brought a range of perspectives and interpretations of the development of the DPA, who had been involved at different times during the DPA's history, and were able to articulate the issues.

Preliminary investigations indicated that the spouses tended to have considerable involvement with the work of the DPA as they supported their partner in their role as President. When interviewing Pauline Angus and Mary Stott I discovered that while they did support their partner to undertake the role of President, this support often took the form of them taking on increased responsibilities in their homes. However both had accompanied their partners on trips, both in New Zealand and overseas, providing support and personal care assistance as required. Despite not having active roles within the DPA, both had an understanding of what their respective partners were trying to achieve. Both recalled having had several meetings graphically relayed to them in their role as sounding boards for their partners. While they may not have had specific information on the workings of the DPA, they contributed richly in reflecting on their partners' contributions. Likewise, Lindsay and Mary Buick-Constable had only a peripheral understanding of the DPA and its activities, but made a valuable contribution in giving me considerable insight into Byron's personality, values and achievements.

This project had a 100% response rate. I think this is partly because of my personal involvement in the DPA, but mainly because of the individuals' commitment to the DPA and their desire to have the development of DPA documented.

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<sup>2</sup> Byron Buick-Constable's widow, Christine, was approached but felt she did not have enough information to participate. Christine referred me to Byron's parents, Mary and Lindsay Buick-Constable.

### ***Pilot Interview***

I contacted one person who lived in my district and had been vice-president at the national level and President at the local level, and invited her to participate in a pilot interview. This person agreed to look at the information I had before making a decision. I followed up a week later, and she agreed to participate. This was a useful process as I had not been involved in research for some time. From that pilot interview I became aware of aspects of my interviewing approach that needed modifying, particularly to focus less on whether all my questions in the interview schedule [Appendix 1] had been addressed in order. Instead I needed to 'go with the flow' of the interview, to allow more space for the participant to direct the process themselves. I will not be drawing on information from that interview in the body of the discussion as the interviewee had not had the experience of being in the role of National President, and did not have the knowledge and understanding of some of the issues being explored in the interview.

### ***Preparing and Conducting the Interviews***

After that pilot interview an invitation to participate in this project [Appendix 2] and an Information Sheet [Appendix 3] was posted to Marilyn Baikie and Anne Hawker who had been President, three surviving partners of past presidents, Pauline Angus, Mary Stott and Christine Buick-Constable, and the current President, Paul Gibson. I indicated in the Information Sheet that I would contact them by telephone within two weeks of sending the material to them. Paul Gibson e-mailed me requesting that I sent the information through to him via e-mail so he could access it (he has a vision impairment and accesses written material via the computer with the use of special software). I contacted all the potential participants by telephone and asked if they were clear about my project, and whether they were willing to participate. During my telephone conversations with each of them I was given their verbal agreement for participating, and I was able to negotiate with them a convenient day and time to meet with them. As Byron Buick-Constable's widow, Christine, declined to be interviewed I instead interviewed his parents Mary and Lindsay Buick-Constable. I contacted them and they were enthusiastic about participating, but a little unclear about the topic of my project. I agreed to send them a copy of the interview schedule so they would have time to reflect on the questions before our meeting. This proved to be a useful prompt. They had

sorted out a lot of material for me before I arrived. As a result of this experience I sent out the interview schedule to the other participants prior to their interview. The participant who had acted in the 'pilot interview' had not been given the schedule prior to the interview, neither had Pauline Angus, the first participant I interviewed.

Mary Stott and Marilyn Baikie lived in Christchurch. Pauline Angus, Lindsay and Mary Buick-Constable, Anne Hawker and Paul Gibson lived in the Wellington region. I arranged two visits to Wellington, interviewing two people during each visit, and one visit to Christchurch, interviewing the two participants on the one day. I conducted part of the interview with Mary Stott on her own, and then Marilyn Baikie joined us. This was helpful in keeping to a tight timeframe, and also meant Marilyn was able to give some support to Mary who was feeling anxious about participating and was apprehensive about not having a clear recollection of events and of some of the issues of the day. Once Marilyn began talking, Mary relaxed notably and remembered things a lot more freely.

Each of the interviews took approximately two hours. The purpose of the interview was to canvass their recollections and explore a range of topics relating to the development of the DPA that addressed the objectives of my research:

1. To trace the development of the DPA in New Zealand
2. To locate this development in the wider picture of social/political and economic developments in New Zealand
3. To identify key people involved in the development of the organisation, and
4. To explore theoretical ideas that are useful in examining the experience of the DPA in particular, and the experiences of disabled people in general.

The interviews were taped. The participants were informed both verbally and in the Information Sheets that they could ask for the tape to be turned off at any time. Before starting each interview I had an informal discussion with each of the participants. This helped both them and myself to relax so as to move into the topic easily. It also gave some time for each participant to complete their biographical details [Appendix 4] and consent forms [Appendix 5]. Participants were asked to indicate if they are willing to a) be identified as having participated in the research for this thesis, and b) have their quotes referenced. All participants agreed to their quotes being referenced when appropriate, signing a separate consent form for this [Appendix 6].

The interviews were completed within a two-week timeframe. This proved to be a demanding schedule for me but it meant I was able to fit around the participants schedules and I was able to keep the number of trips I needed to make to a minimum whilst still achieving my goals.

Once I had completed all the interviews the tapes were sent away to be transcribed. The company who transcribed the tapes completed a confidentiality form [Appendix 7]. I then proofread the transcripts and sent them to the respective participants (Paul was sent his copy on audiotape). This allowed them the opportunity to check for accuracy and to add or delete anything they wished. I believe it is important to make provisions for this process as it is important that control over their information and views remains with the participants. In total, it took the participants 6-8 weeks to return their transcripts with the amendments. Changes made by participants focused on grammar and sentence structure and the spelling of peoples' names; none of the participants made any changes to the content.

The data from the six interviews and archival records was collated and organised into themes. The themes are:

- Historical overview of the DPA
- Philosophy, values and beliefs of the DPA
- Leadership (including individual profiles)
- Successes and ongoing issues for the DPA as part of the New Zealand disability movement
- Future directions

These themes provide the base for my chapters and provide a framework from which to present the discussion and analysis, relating the findings to relevant literature. Spicker (1995) states that qualitative data is generally organised through a process of selection, thematic organisation and interpretation. The final presentation of the data and my discussions take the format of quoting extensively from the six interviews. I have identified when I am making reference to discussion drawn from these interviews, and when using direct quotes I have put the quotes in italics.

## ***Ethics***

Massey University outlines major principles contained within their Code of Ethics regarding research. These principles require that

- a) Informed consent from the participant is obtained
- b) Confidentiality of the data and the individuals providing it is maintained
- c) The harm to subjects, researchers and technicians is minimised
- d) Truthfulness is upheld with the avoidance of unnecessary deception, and
- e) Social sensitivity to the age, gender, culture, religion, and social class of the subjects is upheld.

Historically, disabled people have tended to be vulnerable 'subjects' in research. Oliver (1990) refers to the power of research, and the responsibility of researchers to the researched. In this research prospective participants were sent an Information Sheet outlining the project, its aims, and what their involvement would be should they choose to participate. The Information Sheet outlined how they could contact both myself and my Masterate Thesis supervisors, Mary Nash and Mary Ann Baskerville in the School of Social Policy and Social Work at Massey University, and the Secretariat of the DPA should they require further information or clarification on the project. It was clearly stated that participants could withdraw from the project at any time, and that I was available to discuss any concerns they might have relating to the project. I followed up this written information with a telephone conversation within two weeks of the material being sent to them. At the beginning of each interview I again asked participants if they were clear about their involvement in this research.

Participants in this thesis are well known within the disability community. It is quite possible that, if quoted, they could be identified. In deciding to undertake this project I was committed to using this thesis as a means to publicly acknowledge the people who have been involved in the DPA's development. I believe it is important to be able to locate the contribution of disabled people within the disability community and context of the history of New Zealand. I therefore sought their permission to quote directly from their interview, and also asked for their permission to have their quotes referenced to them by name.

They were asked to sign two consent forms, the first giving their consent to participate in this project and the second form to give their consent to having their quotes used in the final written document, and to having these quotes referenced to them by name when appropriate. All participants completed both forms. In completing these consent forms the participants understood that they were agreeing to let me as the researcher use the information gained for my MSW thesis, and for other subsequent published or unpublished work. If participants had stated they were unwilling to have their quotes used and referenced by name this would have been respected.

In writing this thesis I have been careful when using quotes that make reference to 'politically sensitive' information or observations to check statements with archival data where possible. In some instances I have checked back with the person who made the statements to ensure they were comfortable with their use.

Tapes were kept secure in my home for the duration of the project. Only the transcriber and myself listened to them. At the completion of the project participants were asked if they wish to keep a copy of the taped interview. They were also asked if they wanted the tapes from their interview to be stored in archives at Massey University. If participants did not wish to keep their interview tape or wish to have their tape stored in archives, the tape was destroyed.

The six participants I interviewed were all Pakeha New Zealanders. Of greater significance for this project was the fact that all the Presidents have been disabled people, and as the individual profiles in Chapter six show, all were active members of disability-related groups and organisations. As a disabled person myself, I operate within the 'disability culture' and am known in the disability community, both locally and nationally. I was therefore known (or known of) by the participants, and they identified with me as having been actively involved in the DPA.

I needed to consider the support needs of individual participants due to their impairment. For example, when I interviewed Paul Gibson (who is vision impaired) I incorporated the collection of his biographical details in the interview. As in any research situation, I was sensitive to the participants' needs according to their age, their values and beliefs (including their religious beliefs) and their state of health at the time of the interview. When interviewing the surviving spouses/family members I was keenly aware that they may have found it emotionally difficult at times having to focus

intensely on their memories of them, and in one situation, the surviving spouse was adjusting to their recent loss.

In my initial approaches to the National Executive of the DPA I made a commitment to send a copy of my completed thesis for the organisation to use as they wish. It is my hope that it will be available for the DPA membership and anyone else doing research in the disability arena. I also intend to write a summary of this project to send to participants, and to look to appropriate journals for this summary and any other related papers I write from this thesis to be published.

### ***Participants' Feelings about being part of the Project***

All the participants expressed enthusiasm and support for this research. There was a commitment from them all to see the DPA's development and achievements being documented, sharing my wish to have key players' contributions acknowledged. Paul Gibson used it as an opportunity to reflect on activities he had been involved in during his first year in the role, and to reflect on some of the current issues. Anne Hawker and Marilyn Baikie commented on having some difficulties in remembering past events and activities they had been involved in (I was sometimes able to prompt discussion by referring to background material and drawing on my own recollections and perceptions). Pauline Angus, Mary Stott and Lindsay and Mary Buick-Constable indicated they felt proud to be able to reflect on their family members' contributions, although they were sometimes apprehensive that maybe they may not represent the 'facts' accurately, that they had only a little working knowledge of DPA. Pauline Angus was pleased to have the opportunity to reflect on particular aspects of Quentin's personality, his strength and determination, and his achievements. For Mary Stott and Pauline Angus this project provided an opportunity to talk about the impact DPA had on their families' lives, that to take on the role of National President of DPA takes considerable time and energy. Marilyn Baikie and Anne Hawker also reflected on the toll taken on their families. Finally, participants expressed 'horror' at the number of 'ums' and 'ers' that appeared in their transcripts, while two participants commented on how disjointed the conversation appeared in the transcripts, expressing their relief that they had not had to do the transcribing!

### ***Limitations of this Thesis***

The scope of this thesis resulted in the selection of participants being limited to the leadership within the DPA, specifically the Presidents at the national level since 1983. This means that discussion on the development of the DPA is largely from a 'National Executive' perspective. The DPA is structured to enable disabled people, disability-related organisations, and other interested parties throughout the country to participate in the wide range of the DPA activities (identified in DPA as the regions). This project has not included input from these regions. I am aware that the regional 'grassroots' input is crucial for the National Executive and the Secretariat to be able to identify the issues and concerns, however an examination of the role and functions of regional assemblies will have to remain a potential research project at this time.

Another limitation is that this is the first comprehensive study of the development of DPA since its inception, and it was difficult for the participants to recall a lot of information, particularly from those early days. I was fortunate to be able to utilise the archival data from DPA that allowed me to crosscheck some of the information given in the interviews to ensure accuracy in the recording of events and dates.

Using the life history approach to provide a framework for interviewing the past presidents and the current president of the DPA posed particular difficulties when it came to looking at the lives and contributions of the three past presidents who had since passed away. When interviewing their surviving spouses/family members I used the same semi-structured interview schedule as I had with the other participants. Whilst I was able to access material John Stott and Byron Buick-Constable had written both during their term in office and afterwards, I was largely reliant on third-party interpretations of events. In some instances their surviving spouses/family members considered they had only a limited understanding of their work within the DPA and the wider disability community. However they were able to provide an intimate perspective of their spouse's personality, and their level of commitment to the DPA activities and the impact that had on their lives and that of their family.

### **Conclusion**

In the quest for scientific knowledge social researchers had historically worked from the positivist paradigm, conducting social research as if it was scientific research, looking

for facts and causal relationships. Researchers were seen as being impartial, value-free experts, observing their human subjects and gathering data. Such approaches left research subjects feeling totally alienated and disempowered. This has certainly been the experience for many disabled people where the focus of research conducted 'on them' has tended to be approached from the medical model, where 'disability' is seen as an individual, medical problem. Research working from the interpretivist paradigm focuses on developing an understanding of social phenomena from the perspective of the research participants, where interpretations of events are made by the participants, not the researcher.

When undertaking this thesis I was committed to ensuring that participants were able to represent their own stories in reflecting on their involvement in the DPA and the wider disability movement. I am keenly aware that there is little material published that promotes an understanding of the issues and needs for disabled people, nor the achievements and the contributions of disabled people in various sectors of New Zealand society. It is my intention in the following chapters to do justice to the stories of the six participants, showing how they worked to pool the considerable talents that existed in the disability community to develop an organisational structure for the disability movement in New Zealand.

## Chapter 4

### *Influences that Led to the Establishment of the DPA*

#### *Part A*

### *Setting the Scene*

#### **Historical Approaches to Disability Policies and Issues**

Margaret Tennant (1996:3) observed how

in order to understand these changes it is important to begin by exploring predominant trends in disability policies from the mid-1800s to the early 1980s, identifying significant factors that influenced these policy directions.

This chapter is designed to cover relevant trends in recent disability policies and to place my research in its social context.

Tennant explains that although the settler view of New Zealand was one of an ideal society characterised by pioneering vigour, the reality was often quite different. There were high accident rates leading to permanent impairment or death and repeated outbreaks of infectious diseases also leading to long term or permanent impairment, resulting in those affected experiencing extreme poverty and being ostracised in their communities.

In a brief overview of historical approaches to working with disabled people in New Zealand, Senescall and Spence (1990) identify a twenty year period of relative optimism (1850-1870) regarding the education and training of people with intellectual impairments, after which a period of pity, segregation and abuse set in. They discuss how people with intellectual impairments from 1870 onwards were isolated in institutions set in the country and made to work on farms for no recompense. Tennant (1996) also refers to institutional care for disabled people during this period as being an option available. She notes that such facilities were limited to 'benevolent institutions' providing care for orphans, unmarried mothers and the destitute elderly, and that within this latter category inevitably a small number of younger disabled persons were included. In the nineteenth century disabled people were seen as part of the 'poor', with

their needs being met with minimal financial assistance. From a government perspective, the disabled were supposed to be supported, in the first instance, by their families and then by benevolent societies.

The 1880s saw the development of psychiatric asylums provided by the State, because, as Tennant (1996) notes, psychiatric care held little attraction for voluntary charity. She comments how initially these asylums achieved reasonably high 'cure rates', as many earlier patients were alcoholics drying out, however by the end of the century

there were increasing numbers of psychogeriatric and intellectual handicapped cases featured in admissions (Tennant, 1996:10).

This and the growing predominance of hereditarian beliefs led to asylums being increasingly stigmatised by the association with incurability - an association that continues to undermine disability policy today.

Tennant notes however that at this time moves were made to provide habilitation services, particularly for people with sensory impairments. She cites the opening of a school for deaf children by the Education Department in Sumner (Christchurch) in 1880 and later the opening of the Jubilee Institute for the Blind in Auckland, as examples. From this time on particular groups of disabled people began to be singled out by both the government and the wider community as being 'worthy' of investment. This trend towards institutional care for disabled people, whether focusing on education and training, or on treatment, continued through the early twentieth century.

The twentieth century saw a shift in attitudes towards disability, particularly physical disability. Tennant (1996) highlights how the experiences of two world wars and the outbreaks of epidemics of diseases such as poliomyelitis contributed to this shift, as it was seen that young, healthy people were affected. However she also notes how this had a negative impact on attitudes towards people with mental deficiencies, resulting in moves by the State to identify 'deficient' individuals.

Tennant (1996) discusses early attempts by the State to collect information on the numbers of disabled people through the census, noting that the exercise was not intended to gauge the need for services but rather

it was linked in with concerns about the quality of New Zealand's population (1996:13).

Along with moves to identify 'deficient' individuals and the apparent shift in public sympathy to some categories of disabled people (eg. physical disability), Tennant outlines how the State's response to the needs of disabled people was to expand financial provisions. A range of pensions was introduced such as the Miners' Phthisis Act (1915), pensions for blind people in 1924, and a general invalidity benefit in 1936. This culminated in the introduction of the Social Security Act in 1938. Tennant comments that these developments established

the principle of State support for persons unable to earn a living because of physical incapacity, regardless of age (1996:19).

The interwar years are characterised by an increase in income maintenance policies, a significant increase in the medical interest in disability, and the appearance of national disability organisations that began to play a significant role in advocacy and service provision (Tennant, 1996). She notes how the increase in the medical interest in disability meant a growing research into and optimism about many conditions (eg. poliomyelitis), however it also resulted in a greater likelihood of disabled people being viewed in terms of their impairment. Impairment-specific organisations began to emerge during this time which still exist today, including the Crippled Children's Society (now the CCS), the Soldiers' Civilian Re-establishment League (later the Rehabilitation League, now Workbridge), and the League for the Hard of Hearing.

The government emphasis in disability policies at this time was focused on working with returned servicemen, reintegrating them back into society, and specifically the workforce. Tennant (1996) notes that during this time consumer advocate groups emerged that were not dominated by professionals or those motivated by the charity ethos, but rather, by disabled people and their families. Catran & Hansen (1992) also discussed how the formation of the Association for the Blind and Partially Sighted in 1945 was partly a reaction to the autocratic and paternalistic ways evident in the New Zealand Institute for the Blind.

Another group that formed at this time was the Intellectually Handicapped Children's Parents' Association (later to become the IHC). This Association was significant in that it did not allow anyone other than parents to be members. They began to challenge the practice of placing children with intellectual disabilities into institutions, looking for ways to meet their needs in the community so the children could remain with their families (Tennant, 1996). However, it was not until the 1970s that deinstitutionalization

and 'community care' programmes had greater prominence in government social policies for targeted groups such as disabled people.

## **The Beginnings of a Community Focus**

In 1975 two separate pieces of legislation were introduced that impacted significantly on the provision of services and equipment for disabled people, with the focus being to maintain people in the community. The first was the Disabled Persons' Community Welfare Act<sup>3</sup>. Under this Act an advisory committee made recommendations to the Minister of Social Welfare on services for disabled people. It provided financial assistance to disabled people (through provisions such as suspensory loans to modify homes and to purchase vehicles), to people caring for a disabled person, and to organisations providing support and counselling (such as the CCS and the IHC). Part of this Act was concerned with the provision of disabled access to public buildings and represented a significant shift in recognising the need for environmental change rather than the emphasis always being on disabled people needing to change to 'fit in' (Tennant, 1996).

The second piece of legislation was the Accident Compensation Act. This replaced litigation for those injured in accidents with a no-fault system of earnings-related financial relief and included provisions for lump-sum payments for permanent disability. Under this legislation the Accident Compensation Commission (ACC) was established with responsibilities for rehabilitation. The provisions in this legislation were considerably more generous than those provided within the Disabled Persons' Community Welfare Act, resulting in disparate treatment between those whose impairment stemmed from disease and congenital conditions and those who acquired an impairment as a result of an accident.

In summarising the provision of disability support services at that time - funding was available through the following provisions:

- The ACC

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<sup>3</sup> J. B. Munro who was a Labour MP at that time and later became the vice-chairman of RINZ, supported the introduction of this Act, indicating his intention to introduce a Private Members Bill if it was not successfully passed. Quentin Angus who was active in the New Zealand Council for the Disabled and was instrumental in establishing the DPA, had been part of a working party who wrote submissions on the proposed Bill and later was instrumental in drafting building standards encompassed within the legislation (Angus, 1994:4).

- The Disabled Persons Community Welfare Act 1975 (administered by Social Welfare)
- The Social Security Act 1938 (individual benefits administered by Social Welfare)
- The Ministry of Education (Special Education provisions)
- The Area Health Boards (such as rehabilitation services, the provision of equipment and other domiciliary support services).

This resulted in the fragmentation of services with disabled people being left feeling disempowered. The fragmentation of services was further aggravated with many service providers targeting services to people with a particular impairment (eg. the Royal New Zealand Foundation for the Blind only providing services to those classified as legally blind). This was particularly difficult for those who had needs that could not be narrowly defined to fit into rigid classification systems.

Despite the apparent range of funding sources disabled people had considerable difficulties in proving their eligibility to access services and other resources, and therefore were unable to access adequate supports to be able to fully participate in their community. Related to this was the major problem that services required by disabled people to maintain themselves in the community simply did not exist, as Government funding for 'disability' was usually channelled into segregated, often residential, facilities. As indicated in the preface of this thesis, this lack of community-based services had directly impacted on my own living situation, necessitating my admission into a residential facility for physically impaired people. This facility offered rehabilitation services and schooling, as well as long-term personal care. The lack of community-based services was in spite of the government's emphasis at that time for 'community care' in areas such as mental health and justice, as well as people with physical, sensory and/or intellectual impairments.

### **The 'Consumer Voice' Begins to be Heard**

The 1980s saw "the emergence of a much more vocal consumer voice" (Tennant, 1996:26). While Tennant was referring to the consumer voice in disability, its development can be seen as part of a wider trend for many marginalised groups in the 1970s and 1980s. For example, Coney tells how

the second wave of feminism finally arrived in 1970 with the formation of the first women's liberation groups in several parts of New Zealand (Coney, 1993:121).

Coney discusses how the civil rights movement in America in the 1960s largely inspired this 'second wave'. Campbell and Oliver (1996) similarly conclude that the civil rights movement inspired the development of the disability movement in Britain. I would argue that this is also the case for disabled people in New Zealand. A further catalyst in New Zealand (as in other parts of the world) was the International Year of Disabled Persons<sup>4</sup>. This provided a focal point for disabled people to raise issues and promote their needs. It also provided many disabled people with the stimulus to meet and share their experiences and concerns, providing a valuable platform for group action. For many this was the first step in a process of conscientization. Munford and Sullivan (1997) discuss this process (outlined by Paulo Friere). They explain how, by sharing their stories people develop an awareness that the difficulties they encounter in their lives are due to a combination of social, political and economic factors, and not simply due to their individual deficits as they have often been socialised to believe. Disabled people began to question why services and amenities (such as accessible public transport) were not available, and began making demands to local bodies, government and service providers in the voluntary sector for change. Attitudes and misconceptions that prevailed about disability were beginning to be challenged by disabled people. This growing discontent and the emergence of a vocal 'consumer voice' that was taking its lead from the civil rights movement set the scene for the development of an organisation that was to become the "speaking voice of the disabled" in New Zealand.

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<sup>4</sup> See the following section for discussion on the International Year of Disabled Persons.

## Part B

### ***The Emergence of DPA (Issues & Conflicts)***

#### **An Awakening**

*During the 1960s and 70s it was realised, especially in the districts at the grassroots level, that there was a need for coordination and cooperation between the many disability organisations<sup>5</sup>, Quentin Angus (1994a: 5).*

#### ***The New Zealand Council for the Disabled***

In Part B, three institutions are introduced and examined in relation to the emergence of the DPA, namely the New Zealand Council for the Disabled, Rehabilitation International New Zealand (RINZ) and the International Year of Disabled Persons.

Quentin Angus outlined the first moves that were taken to achieve this goal with the formation of coordinating councils for the disabled in Auckland, Christchurch and Dunedin, closely followed by Wellington in 1972. In her interview with me, Anne Hawker explained that the role of these coordinating Councils was to provide coordinated responses to issues such as education and access while Dr. Robert J. Gregory<sup>6</sup> suggested the Council served the voluntary agencies in the country, especially the smaller of the organisations. Angus (1994a) stated that while there were no formal links between these bodies, a close informal liaison was developed. There were occasions when these coordinating councils worked together, such as in 1975 when they presented a joint submission to Government on the Disabled Persons Community Welfare Bill.

In 1977 the Combined Coordinating Councils (as they were then known) met in Wellington with the specific purpose to consider the possibility of forming a national body. Angus notes that

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<sup>5</sup> *DPA: The Beginning* (1994) sets the scene prior to the development of DPA and outlines its early days. It was published in two parts in the DPA publication *Able Update* (February/April 1994).

<sup>6</sup> Dr. Robert J. Gregory is senior lecturer in the School of Psychology, Massey University, Palmerston North, New Zealand. He began writing *Rehabilitation International New Zealand: Stimulus to the Disability Movement* in 1995 and describes it as a work still in progress.

the visit to New Zealand of Mr. F. Lionel Watts MBE, an Australian quadriplegic... who was also actively involved in ACROD, the Australian Council for the Rehabilitation of the Disabled, gave added impetus.

Another precipitating factor was the offer of \$400,000 of Telethon funds to establish aids and information centres, provided that the Combined Coordinating Councils... became incorporated. (Angus, 1994a: 5).

Thus, the Combined Coordinating Councils became the New Zealand Coordinating Council for the Disabled, and were incorporated in 1978.

### ***Rehabilitation International New Zealand (RINZ)***

While the purpose of forming the New Zealand Coordinating Council for the Disabled was to have a body presenting a coordinated response to issues nationally, it was also recognised by some that it was important to have a coordinated body to represent New Zealand internationally. Angus relays how later that year

... the New Zealand Crippled Children Society Inc.<sup>7</sup> called a meeting at Wellington of representatives of national organisations (the New Zealand Council for the Disabled was given 'observer status') with the objective of forming a national body to represent Rehabilitation International in New Zealand. The meeting failed to resolve that a new representative national body be formed.

The New Zealand Council made its claim to represent RI, but the Crippled Children Society and other national societies were not prepared to accept the Council as the RI representative. Possible reasons for the lack of support were that they considered that the Council should not have permitted the smaller organisations to join as members, and that the Council was too much influenced by what were termed 'consumer interests' (Angus, 1994a: 5).

Gregory (1995:13) also discusses the tensions evident from the national organisations to the Council, particularly from the larger organisations such as the IHC. He suggests that the decision to go with RINZ and then later an IYDP committee as a separate entity may indeed have been encouraged by IHC, which apparently saw the coordinating

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<sup>7</sup> A national service provider organisation working predominantly with physically disabled children, and later working with adults too.

councils as not being in line with their own interests and perhaps outside of their control.

It can be argued that these examples of barriers that resulted in the coordinating council being denied the recognition as a credible organisation capable of representing the interests of disabled people nationally and internationally are significant. It illustrates the difficulties at that time in getting organisations to work cooperatively and the reluctance of service provider organisations to work with their 'consumers' (parents of disabled people and disabled people themselves) as active participants in decision-making arenas. These examples also allude to the level of power plays that were occurring at this time between the larger voluntary organisations (and some of the personalities) within the sector.

Angus (1994a) explains how in the late 1970s the Rehabilitation League (New Zealand) Inc. was operating as a quasi-government agency. Gregory states that the Board of Management of the Rehabilitation League was advised that the government's policy be

that the Board should facilitate the representation of Rehabilitation International in New Zealand by appointing a standing committee to be known as Rehabilitation International New Zealand... for the purpose of advising the Board on all matters relating to the representation of Rehabilitation International in New Zealand... (Gregory 1995:3).

Gregory (1995:3) states that RINZ had a number of roles. Among other things, they were to:

- Advise the government on ways and means to achieve objectives such as the promotion of the rehabilitation of the disabled;
- Organise, plan, sponsor and encourage national and regional conferences; encourage research into the causes and prevention of physical and mental disabilities;
- Work to improve of the status of disabled persons by promoting their integration into the community and 'their relief from want'; as well as to
- Promote the 1981 International Year of Disabled Persons in New Zealand.

It was intended that RINZ would only exist for the International Year of Disabled Persons (IYDP). Byron Buick-Constable (who later became president of DPA) was the chairman of RINZ with J. B. Munro (Chief Executive Officer of the IHC, who was later

to be on the DPA National Executive Committee) as the vice-chairman. Gregory commented that there was little duplication between RINZ and the New Zealand Council for the Disabled.

... given the lofty goals and purposes of RINZ and the community focus of the New Zealand Council for the Disabled (Gregory, 1995:4).

### ***International Year of Disabled Persons***

The United Nations, as part of the Decade of Disabled People, created the IYDP. Its purpose was to raise the profile of disabled people internationally, to celebrate their achievements and to promote the needs and issues of disabled people within their communities. It was seen by many in the disability community as being a landmark in the history of the disability movement (Hawker cited in Beatson, 1997; Stott cited in Beatson, 1998), not just in New Zealand but throughout the world. The New Zealand Council for the Disabled was a member of RI and so participated fully in the IYDP (Angus, 1994a).

Rehabilitation International New Zealand established an IYDP National Committee as a separate entity and in June 1980 Ken Munro was appointed as its Executive Officer. The committee chose to focus on six prominent areas of interest: access and mobility, accommodation, education, vocational issues, benefit assessment, and prevention. The theme for the year was 'Full Participation' (Gregory, 1995).

The national committee divided the country into regions (corresponding to the New Zealand Rugby Football regions) and actively promoted the development of regional committees. The aims of these regional committees were to include:

- Action to achieve the aims of IYDP; to
- Actively seek the cooperation of and coordinate with the already well established organisations; and to
- Assist in the involvement of the disabled themselves in planning and action at the regional level, and to promote the establishment of local committees (Gregory, 1995:5).

In New Zealand a Telethon was held to raise funds for projects organised by disability-related groups and for individual disabled people. Although it was just one project in

the IYDP schedule, for some the telethon became a focal point for the year. This created some dissension, as Anne Hawker explains in her interview with me.

*... I think that this is the disadvantage with having a Telethon, that it created some adversity, because some people were so desperate to get money for their little groups...*

In spite of this, Anne believes that New Zealand's active involvement in IYDP had a positive impact for disabled people.

*It said to people with disabilities that you matter, that you are people and you are part of society... There was a lot of hard work but it was also a celebration... All the issues that were raised, the work that was done...*

John Stott (in Beatson, 1998) also saw IYDP as being a positive turning point, both for himself and other disabled people. He stated that

I chaired the Southland IYDP regional committee and became conscious that places like Invercargill had hundreds of disabled people of whom I had not previously been aware... (Beatson, 1998:7).

Gregory accessed speech notes from Ms. Ann Ballin, Chairman of the National IYDP Committee, where she outlined what she saw were the benefits that came from IYDP.

This IYDP has given us all the stimulus to reappraise our knowledge of disability in all its forms and all its ramifications, its effects upon the disabled people and their families and the impact on the community socially and economically... it has enabled this country... to take stock of its attitudes and its awareness (Gregory, 1995:5).

Later in his paper Gregory quotes from an article Ballin wrote, where she concludes that

...1981 gives us all, no matter whether we have present personal involvement or not, an opportunity to ponder upon the important facets of disability. We will then be in a better position to influence our own society, remembering that not one of us is immune to disability, especially as we age (Gregory, 1995:15).

Gregory's paper identifies many working groups, sub-committees and the like that were created during this time to explore the wide range of issues facing disabled people. He gives an example of a meeting held at the NZ Association of the Blind and Partially Blind Offices in Parnell on 17 September 1981 in which Don McKenzie (who was later

to become vice-president of DPA National Executive Committee) was a key player. Gregory describes how

a band of 17 individuals met to 'explore common points of interest' and in the discussion, grassroots support for national levels of organisation was paramount... No existing council was felt able to do the job that the group had in mind... If the existing group was Government funded then it was likely to be Government controlled. The discussion examined organisations in the USA, with mention of the power held by the groups OF the disabled [his emphasis]; that they have 'clout', and use it (Gregory, 1995:15).

Gregory continues, explaining that the Party then moved that

"... in order to continue projecting the ideals of IYDP there be established a CROSS-DISABILITY MOVEMENT [his emphasis] to represent and promote the interests of people who are disabled on matters pertaining to the well-being of disabled people." They specifically mentioned that the users interest should be most important and that existing groups which agreed to alter their constitutions to reflect this proposal were worth considering (Gregory, 1995:15).

However, Stott was disappointed that in 1982 the same level of activity and the participation of disabled people were not maintained. He felt that many people went back into their shells, that people were so focused on activities for 1981 even though the United Nations had dedicated the decade 1981-1991 to disability. Reflecting on his own involvement, Stott noted:

we should have used 1981 as a base, then followed it up over the next 10 years. We put too much effort into raising expectations for IYDP, as though that were our only chance. Events in later years would inevitably have been less intensive... but 1981 could have been an important springboard for future activities. (Beatson, 1998:8).

## **DPA is Born**

Although Stott felt there had been lost opportunities, both he and Angus assert that the DPA was formed out of the initiatives that had begun during IYDP, and was born out of the consciousness-raising among disabled people that occurred (Beatson, 1998:8). Angus (1994b) explains that as it was not appropriate for a Standing Committee to either represent New Zealand at international forums or to make representations to

government. He believed that the disability groups, which had worked together during IYDP, provided a foundation from which a national organisation representing both local organisations and individual people with disabilities could be developed.

In November 1981, as IYDP drew to a close, the RINZ committee was asked to consider possible future directions for the organisation. People such as Cynthia Purdom (National Field Officer of NZ Riding for the Disabled) saw the future of RINZ

... as an information server and a link with International services for disabled... with the ability to represent the various government and private agencies, the opinions and expressed needs of the various disabled consumer members of member organisations... to provide guidelines which may help to change policy in areas related to disability... (Gregory, 1995:16).

However, Angus, in a two page document to RINZ (Gregory, 1995) stated he felt that it was necessary to have a completely independent body to represent RI. He argued that there was a need for a national independent body to represent disabled persons while RINZ continue to represent RI. Angus stated that

... with the cooperation of the New Zealand Council [for the Disabled] RINZ could become the principle source of information, and with the cooperation of RINZ, the New Zealand Council could develop its role as the national representative voice of the disabled themselves, supported by those organisations which are or become members of the NZ Council. This will give the various national organisations the option of belonging to either or both of RINZ or the New Zealand Council, and these two bodies will have their broad separate, but nevertheless complementary functions (in Gregory, 1995:16).

Angus (1994b) explains that a series of meetings was held in 1982 between representatives of an ad hoc cross-disability group of people with disabilities, RINZ, and the New Zealand Council for the Disabled with the view to establishing this proposed new national organisation. As the president of the New Zealand Council for the Disabled, Angus was a key figure involved in these negotiations. Angus highlights an earlier incident where a major division between disabled people and the representatives of National Affiliate Organisations occurred at the international conference of RI in Winnipeg in 1980. This incident sent ripples throughout the

rehabilitation and the disability world, including New Zealand, and was a significant influence in these discussions. He explains how the division was caused

... by participants with disabilities requesting the right to participate in the operations and structures of Rehabilitation International. They believed the organisation was not listening to the voice of the consumer and was not including them in the decision making process on matters that affected them... (Angus, 1994b: 6).

The effect of this division on the international stage was the establishment in 1981 of Disabled Peoples' International, which set in place an organisation which Angus (1994b) argued spoke for people with disabilities at both international as well as national levels.

Angus (1994b) relayed how Mr. Bill Maddren who had been Secretary to the New Zealand Council for the Disabled had attended the Winnipeg conference representing the Rehabilitation League as part of the New Zealand delegation. He returned from that conference convinced that the New Zealand Council for the Disabled was on the “right track” to cope with likely future developments because of its encouragement, not only of national and local organisations, but also of disabled people as individuals. Angus continues, explaining that

...the stage was set for the constitution of an appropriate body to represent people with disabilities both within New Zealand and overseas, to be achieved ultimately by the New Zealand Council [of the Disabled] offering to modify its Constitution... (1994b: 6).

In spite of Angus's optimism, the road to establishing DPA as a national organisation was not smooth, as Pauline Angus recalls in her interview with me.

*... I often think of that period as blood, sweat and tears as my word there were a great number of fairly forceful characters who said quite plainly that there was no room for handicapped people to be in the actual nuts and bolts of a committee organising things for them, and it was to eliminate [that attitude] that was... the driving force, and when everything came to fruition, not without some very hot tempers and hot words... But in the end the whole thing gelled and I was amazed later to find that some other places overseas looked on at what had happened in New Zealand as being a very good thing and something to follow.*

And so it was that at an Extraordinary General Meeting of the New Zealand Council for the Disabled on 21 March 1983 a resolution was passed confirming that the Council would be known as the Disabled Persons Assembly (New Zealand) Incorporated. The Council's constitution was altered to adopt the new name, with few other changes being made. Quentin Angus remained as president until the first Annual General Meeting of DPA on 15 May 1983 in Hamilton when he stood down, and was succeeded by Byron Buick-Constable.

## **Conclusion**

This chapter outlines key trends that informed various responses from governments and the voluntary sector to the needs of disabled people from early colonial times through to the early 1980s. Initially there was an overall reluctance on the part of government to recognize that disability existed in this 'land of promise'. With the advent of recessions in the late eighteenth and early nineteenth centuries it was acknowledged that there was poverty in New Zealand that required a government response. As was the experience in Britain, systems were established that were intended to distinguish between the deserving and undeserving poor. Thus began the medicalisation of disability.

Margaret Tennant outlines the development of impairment-specific service providers that tended to be based largely on a charity ethos as was expected by governments at that time. She shows how this approach changed in later governments, especially from 1915 to 1938 with the introduction of comprehensive financial provisions, albeit that they were framed in rigid moral judgments.

From as early as 1945 we see the development of consumer-driven groups such as the Association for the Blind and Partially Sighted. Individuals dissatisfied with existing services and who had a desire to challenge structures and work for change initiated these consumer groups. The 1970s and 1980s saw groups run by disabled people for disabled people emerge. They were able to utilise experiences and strategies from overseas developments such as the civil rights movement in America and New Zealand-based movements such as the women's liberation movement. At that time there was widespread concern from disabled people over issues such as the fragmentation of disability services and the lack of opportunities for them in education and employment. It was also recognised that there was little coordination of services for disabled people in both the voluntary sector and State sector. It can be argued that the emergence of the

Disabled Persons Assembly in 1983 provided a focal point for the disability community from which to organise political action, and provided an opportunity for disabled people to build strength and unity amongst themselves.

## Chapter 5

### ***The Structure of the Disabled Persons Assembly and the Underpinning Philosophies, Values and Beliefs***

*IYDP 1981, was just the beginning. DPA is the continuation, the action is tomorrow and it is in our hands* (Munro, 1983:30).

### **Philosophy and Vision**

The DPA incorporates four main groups into its membership, comprising of individual, corporate, family and associate members. These categories of membership, which are outlined later in this chapter, represent a range of interests from disabled people to those of service provider organisations working with disabled people. Its Constitution and records from its first conference in 1983 reflect the organisation's intention from the outset to ensure that the interests of this diverse membership are represented. A philosophical base has therefore evolved from which DPA has identified key roles for itself in the disability community and the wider public and political arenas.

The Disabled Persons Assembly has as its motto "We Can". Its stated vision is for New Zealand to be "a society which provides both equity and maximum opportunity to participate for all people", and its mission is to promote policies that "enhance and dignify the lives of people with disabilities"<sup>8</sup>. In the interviews I conducted the respondents identified some key themes when discussing the philosophy of the DPA. For Marilyn Baikie the key theme is empowerment.

*...Empowering people with disabilities to be as independent as possible, and to have the power in decision-making.*

Don McKenzie at the inaugural DPA meeting also expressed his view of the goal for empowerment for disabled people.

When people are hungry, don't give them fish; give them a fishing line so that with patience and compassion those people can learn to help themselves. They are given the dignity and the opportunity to develop their potentials and to become equals in the partnership of life (McKenzie, 1983:16).

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<sup>8</sup> Its Vision and Mission Statements appear at the beginning of all publications.

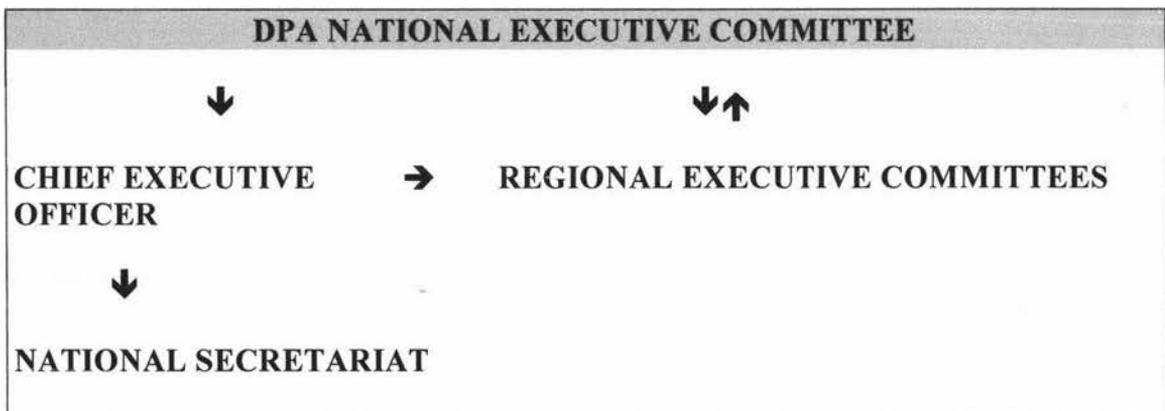
In her interview Pauline Angus reflected how Quentin shared a similar view.

*I think the word dignity was the word that he used and that concerned him right from the beginning... Dignity for disabled people to participate in every way possible, whether it was business, pleasure, plain living, sport; he felt that there had been too much time wasted and too many valuable people lost because the whole attitude was they needed looking after.*

## Organisational Structure

The founding members of the DPA were anxious to develop a structure that would promote democracy at the various levels of the organisation, enabling maximum control of, and participation by disabled people in the organisation. As a national organisation the DPA has a centralised governing body, the National Executive Committee which is supported in its administration by the National Secretariat. The Secretariat is coordinated by a Chief Executive Officer, supported with the permanent position of a secretary, and part-time positions of a journalist and a researcher. Facilitating the work of the DPA at the local level are currently 35 Regional Assemblies throughout the country. Of these, 22 have an active Regional Executive Committee (Disabled Persons Assembly (New Zealand) Inc, 1997-1998). The regional executive committees report regularly to the National Executive while still operating with a degree of autonomy. The structure is illustrated in the organisational flow chart in Figure 1 below.

**Figure 1. DPA Organisational Chart**



## **Membership**

An examination of the membership structure of the DPA provides a clear illustration of the underlying principles upon which it is based. The Disabled Persons Assembly (New Zealand) Inc. is unique both in New Zealand and internationally in that it is a non-profit umbrella organisation representing disabled people and their families, organisations involved in advocacy on behalf of disabled people, and service providers. It is an organisation encompassing people with all impairments – physical, sensory, intellectual, psychiatric, neurological and age related. At the DPA's inaugural meeting held in Hamilton in 1983 Quentin Angus<sup>9</sup> stressed how this composition of the organisation's membership represented an important partnership that will

... hasten the dispelling of the unwarranted mystique which has grown up around disability. It is only when disabled people and able-bodied people actually meet and talk together... live in the community in a non-segregated situation... that the full realisation dawns that we are all persons... This is the only way that attitudinal barriers are broken down... (Angus, 1983:12).

Don McKenzie<sup>10</sup> also addressed this meeting, and in discussing the DPA's membership stated:

we are interested in building a stronger society based on understanding, tolerance, dignity, challenge and full citizenship for all. Let it be understood from the outset, DPA is a forum for everybody concerned with the well-being of disabled persons. The non-disabled are an essential component in the formula. We are interested, not in differences but in common goals – goals that are realistic and achievable (McKenzie, 1983:16).

Representatives from the Asia Pacific region of the Disabled Peoples' International who attended the inaugural DPA meeting also acknowledged the DPA's unique composition of its membership, congratulating the organisers on their plans to incorporate disabled people and non-disabled people (including service providers). Ron Chandran-Dudley<sup>11</sup> stated:

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<sup>9</sup> For an overview of Quentin Angus's involvement in the establishment of the DPA and his extensive contribution to the wider disability community, see chapters four and six.

<sup>10</sup> Don McKenzie was a founding member of the DPA and at the inaugural AGM he was elected as DPA's first Vice-President.

<sup>11</sup> Ron Chandran-Dudley was the International President of the DPI.

... you are in fact creating an historic event by bringing together equal components into forming a solid whole. You have put down the foundations under what my friends called 'my castles in the air' when discussing the bringing together of service providing agencies and organisations of consumers (1983:21).

Another DPI representative who attended this inaugural meeting, Professor Charlotte Floro, observed how internationally planning for the eighties was taking place in a deliberate fashion, based on the principles of cooperation, coordination, collaboration and communication. Floro stated she believed the development of the DPA manifested those principles "in a striking and real way" (1983:31).

In spite of this positive atmosphere, the inclusion of non-disabled people, including service providers, in the DPA membership has created some tension throughout the DPA's existence. John Stott (cited in Beatson, 1998) noted how the question of service providers having full membership rights in the DPA has been debated at National DPA meetings on at least two occasions, and that the membership has voted to maintain the status quo. John stated that he believed disabled people did not achieve as much as a separate group as they have been able to in collaboration with other groups.

Campbell and Oliver discuss this issue at length. They warn:

... before you can develop a clear understanding of disability, the group most concerned needs to address it and look at it and understand it. But if you bring others in before its done that, then because the group is an oppressed group, it will have less experience and less capabilities than the other people who have come in, and they will modify it on their terms. So if you have able-bodied people included within... the experiences they will bring, their perception will modify the group...(Campbell & Oliver, 1996:67).

While the people instrumental in forming the DPA were able to clearly state the principles that were to become the foundations on which the DPA was formed, I think it is recognised by many that this level of political activity was new to many disabled people. I believe that disabled people needed to have the space in which to debate key philosophies and values before coming into this 'partnership'.

There are four categories of fee-paying membership within the DPA and each category has a separate and different fee structure. Fees are determined at the National Annual General Meetings. The categories are as follows:

- *Individual membership* - Any person whether they have a disability or not. Applications are made to the Regional Executive Committee in which the person resides. If a majority of the Regional Executive Committee vote in favour the applicant will be accepted as an individual member, provided that at all times the majority of individual members in the region shall be people with a disability or the parent or guardian of a person with a disability. The regions retain individual membership fees, and individuals are only entitled to one vote at any General Meetings of the DPA's national and regional assemblies.
- *Family membership* - Two or more members of a family (where one or more family members have a disability) constitute family membership. Again, applications for membership are made to the Regional Executive Committee in which the family resides and the Regions retain their membership fees. Family members can appoint two representatives to vote on behalf of the family at all General Meetings of the DPA's national and regional assemblies.
- *Corporate membership* - This is defined as any society, association or other body of persons whether corporate or non-corporate which is a non-profitable, charitable or welfare organisation, whose objects are similar to the objects of the DPA or who work in any way for the benefit of people with disabilities. Such organisations must apply to the National Executive Committee in writing for membership. If these organisations have regional or branch structures their national body can have corporate membership with the DPA, and their branches can belong to the DPA's Regional Assemblies as corporate members, so organisations can potentially have representation on both the National Executive Committee and the Regional Executive Committees. Corporate membership fees go to the National body. Corporate members can appoint one or more delegates to speak and to vote on its behalf at all General Meetings of DPA's national and regional assemblies. Corporate membership fees are assessed according to the number of members in their organisation, as are the number of votes the organisations are entitled to at any General Meetings of the DPA's national and regional assemblies.
- *Associate membership* - Any person, society, association or other body, whether corporate or non-corporate, who is interested in the work and activities of the DPA and desires to be associated with the DPA. Corporate organisations apply to the

National Executive Committee; locally based organisations apply to their Regional Executive Committee.

Again, the Regions retain Associate membership fees. Associate members who are organisations may appoint one person to take part in discussion on its behalf at General Meetings and individual associate members shall also be entitled to speak. No associate member has any power to vote.

Further to these categories, there is an informal non-paying category known as 'complementary members'. This group consists mainly of Members of Parliament, political parties, media organisations, libraries, and other groups and organisations the DPA has targeted as a means of getting information to them (or the individuals or organisations have requested to regularly receive information). This category is not recognised in the DPA's constitution. At the time of writing the DPA Secretariat was investigating the possibility of charging this group a fee.

As noted earlier, the membership fees are divided between the regions and the National Office, depending on the category of membership (eg. individual membership fees being retained by the regions). This means the regions are responsible for maintaining communication with the individual members. Any publications produced by the National Office are sent to regional assemblies for distribution. The regions forward the paperwork from individual members to the National Office that is responsible for maintaining a membership database. This becomes difficult if regions do not forward the information to the National Office at regular intervals, and is further complicated whereby at the time of writing the database was maintained by an individual on a voluntary basis and was not physically stored at the National Office. The corporate membership is solely the responsibility of the National Office with publications and written communique being sent directly to the corporate members from there. Regional assemblies maintain contact with corporate members in relation to projects and events happening in their respective regions, however as the corporate membership fees go to the National Office there is little direct incentive for the regions to follow up with corporate members to ensure their membership is current.

Angus (1994b: 7) stated that the DPA had "... some 600 corporate members and some 1000 individual members". However by 1998/99 the DPA had 604 corporate members, 564 individual members and family/whanau members, 95 associate members and 81 complementary members (this category has gradually increased over the years). These

figures leave the DPA open to being challenged on its claim that the organisation is “the speaking voice of the disabled”. In his interview Paul Gibson acknowledged that membership is an issue that the DPA needs to confront.

*It's the DPA [national] presence that has kept the organisation going, supporting regions and trying to boost membership. A lot of my work has been in that area at the moment. DPA's membership was going down and that's a worry. We do need to... our credibility depends on a large membership, a large active and informed membership. So we're working on that.*

### **The National Executive Committee**

The National Executive Committee consists of a president and vice-president, (who are ex-officio members of all sub-committees and Regional Executive Committees), the immediate past-president and eleven committee members. Elections are conducted by a postal vote prior to the Annual General Meeting. This process was set up in recognition that there were many disabled people who had great difficulty in travelling and attending conferences and meetings. Don McKenzie (1983), in his address at the inaugural DPA meeting, identified this group as the ‘homebound’, a group that the DPA expressed a strong commitment to in discussions in that first meeting.

Only individual members, family members or representatives of corporate member organisations are eligible for nomination for the National Executive Committee. The constitution makes provision for the National Executive Committee to appoint a Maori Adviser (primarily to represent Maori members) as a fully participating member of the committee for a term not exceeding two years.

The constitution [Appendix 8] states that the total membership of the executive committee, including the president, vice-president and the immediate past-president have to have as a majority people with disabilities (or the parents or guardians of people with disabilities). In his address at the DPA’s inaugural meeting Don McKenzie explained how part of the reason for this was so the DPA could be affiliated to the Disabled Peoples’ International. This body requires member organisations to have their governing boards be made up of at least 51% of disabled people. He comments how

this requirement is a significant change from the norm... As far as the affairs of the disabled are concerned, there are many cobblers able to fashion shoes but only the wearer knows where the shoes pinch (1983:16).

McKenzie goes on to explain that

first, the membership requirement which favours disabled people. Some people would say it is quite unnecessary. But the facts show very clearly that disabled people tend not to be consulted on matters concerning their well-being... (1983:16).

However, the National Executive Committee is also required to have as majority representatives of corporate members. This seemingly contradictory requirement was incorporated with the intention that this would represent a true partnership between disabled people and service providers within the organisation. My inquiries revealed it was anticipated that to require a majority of both disabled people and corporate members on the executive would provide the incentive for corporate bodies to nominate disabled people as their representatives. It was felt that it would also ensure that disabled people would become more active in the decision-making within its corporate organisations. Further, these two majorities qualify the DPA for membership of Rehabilitation International and Disabled Peoples' International. However, it can be argued that this situation creates a potential conflict of interest between the needs of disabled people, their families, and those of the organisations as the organisations expect their representatives on the DPA (locally and nationally) to present their organisational viewpoint. In an election the Returning Officer (the Chief Executive Officer) has the power to appoint the next highest polling candidate who meets the required criteria for the composition of the committee at that time.

Elections occur annually with five committee members retiring from office each year. Those who retire have completed a two-year term. A retiring committee member is eligible for re-election. In 1995 the National Executive Committee developed 'terms of reference' from which they work and a general job description for committee members. Committee members informally confirm their agreement to the terms of reference and their responsibilities outlined in the job description once their position on the committee is confirmed.

As well as being the central governing body, the National Executive is responsible for developing policies and

... liaising with central and territorial Government, community, private organisations, corporate and individual members when matters of mutual interest or concern have been identified (Disabled Persons Assembly (New Zealand) Inc., 1995).

### ***Regional Executive Committees***

The constitution makes provision for the National Executive Committee to consult with its membership, to divide the country into regions and to define boundaries for each region. These boundaries are still largely defined from the original IYDP committee regions (based on the New Zealand Rugby Football Union), with 'regions' applying to the National Executive Committee to be recognised as such. As noted earlier, Regional Executive Committees were established in order to coordinate the work of DPA at the local level. In his address at the inaugural DPA meeting Byron Buick-Constable emphasised how coordination at the local, regional and national levels of 'all things pertaining to the disabled' was an important strand of what the organisation was attempting to achieve (Buick-Constable, 1983:14).

Corporate and individual members within a region elect regional Executive Committees. These committees consist of a president, vice-president, and secretary/treasurer and up to eleven committee members, (with a minimum of six members). As with the National Executive Committee, regional committees are required to have as a majority people with disabilities (or the parents or guardians of people with disabilities) and have as a majority representatives of corporate members. Regional assemblies are seen as the 'grassroots' of the DPA, having a crucial role in gathering information and anecdotal evidence to use when making representations to local bodies and organisations. The National Executive Committee and the Secretariat rely on this information when developing policies and consulting with governmental and non-governmental bodies. In my informal observations of the regional assemblies it appears that some work extremely well, presenting issues and concerns from their local region. However there also appear to be significant difficulties in some regions in accessing resources and having a broad membership base to share the workload. The constitution allows for the National Executive Committee to delegate powers and duties to the regions, however the regions are not able to enter financial agreements without prior approval from the National Executive Committee, and they are required to send financial and other reports regularly to the National Executive.

## **Funding**

In order to understand the DPA structure it is important to briefly examine its funding base. During the 1980s the DPA received the bulk of its funding through grants from government (via the Ministry of Social Welfare), with the rest of its funds coming from membership fees, donations, and grants from private trusts. This funding was applied for by the Chief Executive Officer under the direction of the National Executive Committee to be used at the national level. However regional committees also sought funding in their own right for local initiatives from government departments and funding bodies, both national and regional. From 1989, changes in government policies to purchase specific services from organisations (both profit making and non-profit organisations) rather than providing grants for general organisational operational costs had a significant impact on the DPA. Until then the DPA were not involved directly in service provision, avoiding being in direct competition with its corporate members. This stance also had a philosophical base, whereby the DPA wanted to be seen to be neutral in relation to service providers, by promoting the needs and issues of disabled people at the governmental and community levels. The shift to having to contract with government departments to provide services in order to receive any government funding resulted in the DPA as a national body now being contracted for three main functions: advice to government, monitoring services and international representation (John Stott in Beatson, 1998). Regional committees may also contract with government departments and local bodies (in consultation with the National Executive Committee) in their own right to provide services such as providing advice and monitoring services and facilities at the local level.

In 1995 the DPA established a subsidiary company called Maxeq. The draft business plan (Williams, 1999) for Maxeq describes the company as a consultancy providing advice, project management, research, and database services (including the collation and reporting of information for specific projects) to clients including government Ministries and agencies, local and regional government, and commercial entities. In the plan it outlines how Maxeq has undertaken projects to advise on the structure of purchasing agreements or compliance with legislation such as the Human Rights Act (1993), the Building Act, the Education Act (1990) and the Health and Disability Act (1991). The business plan goes on to discuss how Maxeq is a Limited Liability Company that is 60% owned by DPA (NZ) Inc, with the remaining 40% being privately

held. As a subsidiary company of the DPA it would maintain an ethical consistency with the DPA. It is envisaged that Maxeq will be progressively sold back to the DPA at some future date. To date the company has not been active, but discussions with the current Chief Executive Officer indicate that investigations are now occurring to activate the company in order to generate income for the DPA.

## **DPA's Role**

The constitution identifies objectives the DPA works to that have been translated into philosophy statements which the DPA see as being essential in order for people with disabilities to achieve maximum opportunity to participate in society. These philosophy statements outline what the DPA believes are the minimum conditions in order for its mission statement to be attained.

- That people with disabilities must have the right and the opportunity to influence and shape policy at all levels;
- That people with disabilities need to enjoy equality and full participation;
- That people with disabilities need to make informed choices on issues;
- That people with disabilities need to enjoy dignity and respect as a person; and,
- That people with disabilities need to live as they choose with the appropriate supports.

A number of key roles are identified that set out how the DPA organises its activities and projects to implement these broad philosophical statements. The roles are set out on the DPA website (<http://www.dpa.org.nz>) and are organised into the following categories.

### ***Information and Advice***

DPA ensures

- DPA members are well informed about new developments relating to issues that affect them - in New Zealand and overseas.
- Effective representation of the views and aspirations of people with disabilities to service providers, Government, the general public and the media.

At the inaugural DPA meeting, Byron Buick-Constable (1983) identified the need for accessible information, as well as the need to gather information on the issues for disabled people.

Information, communication and total mobility – if information is power we should ensure disabled persons get the things they are entitled to...

In all this I want to ensure that the disabled community promotes a strong, positive and responsible voice that will enable us to achieve all those things dear to our hearts without prejudice, alienation, rancour or anger. There is a lot of responsibility on the shoulders of all members of DPA to make this thing work, at the national, the regional and the local levels...(Buick-Constable, 1983:14-15).

One mechanism the DPA implemented within the first year of its operation to achieve this goal was to establish links with Members of Parliament and government departments. The Minister of Social Welfare of the day and spokespeople from the opposition attend the DPA conferences and AGMs. A system was also established whereby key personnel from government departments such as Social Welfare, Education and Foreign Affairs were co-opted as advisers onto the National Executive Committee. This was intended to ensure the various departments understood what the DPA was trying to achieve and to assist the DPA in accessing political decision-making processes, facilitating a cooperative system of information sharing. This arrangement appears to have ceased by 1988.

### ***Coordination and Cooperation***

DPA promotes

- Coordination of service provision at a local, regional, national, and international level - to minimise duplication and advance the quality of community services.
- Coordination and cooperation of non-government and government organisations - to ensure the views and aspirations of people with disabilities are heard.

In his address to the inaugural DPA meeting Don McKenzie (1983) outlined his vision on how the DPA would work to meeting this goal.

This Assembly has the potential to provide the Government with a consensus point of view on disability related matters. Agency providers and service users have the

opportunity to come together with one objective in mind, namely: to better serve the well-being of this country's disabled citizens by the proper use of available resources fairly allocated (1983:17).

### ***Strategic Planning***

DPA strives for

- Effective input from people with disabilities into Government's policy development and strategic planning processes.

At the inaugural DPA meeting Byron Buick-Constable (1983) identified the need for disabled people to have input into Government's policy development, seeing this as another important strand of the DPA.

... Influence on policy-making both in regard to the organisations which make up DPA and our role in rehabilitation coordination...

There is no reason on earth why disabled New Zealanders should not be seen as part of official New Zealand. Why should we have special places on the procession route? If we were invited to many of the functions (which we are often unwittingly excluded from) there would be no need for such provisions however kindly meant... (1983:14-15).

In her interview with me, Anne Hawker emphasised how this was represented best in the phrase "nothing about us without us". She noted that this was reflected in the Policy Manual that was developed in 1995 as a joint venture between the regional assemblies, the National Secretariat and the National Executive Committee. In her foreword to the Policy Manual, Anne (as National President at that time) said it should be seen as a living document which expresses what the DPA wishes to achieve in specific areas. It was seen that the DPA could use these policy statements to develop strategies and timelines in working towards achieving their stated vision. As well as setting a clear direction for the organisation's work the Policy Manual outlines what the organisation stands for to all external bodies including providers, Government, the media. In 1999 the National Executive Committee developed "Our Vision" – a document which identifies key areas the organisation believes should be the focus for future governments. It was produced as a political manifesto, and is currently being distributed to personnel in the four major political parties.

## **Monitoring**

DPA undertakes

- Monitoring of legislation, regulations and codes of practice and their implementation - to ensure they incorporate the principles of equality of access, effective participation, and economic independence (for people with disabilities).
- Monitoring of disability services to ensure they are designed to enable people with disabilities to have a full, meaningful and constructive life of their own choosing.

At the inaugural DPA meeting Don McKenzie identified that a key role for the DPA was the monitoring (and providing feedback) of services that have such impact on disabled peoples' lives.

...Disabled people must join the contest for resources, give some priority order to their needs, plan services to fulfil those needs, be involved in the delivery of those services and measure the effectiveness and appropriateness of those services (1983:17).

## **Self-Advocacy**

DPA promotes

- Self-advocacy as the strongest and most effective form of communication.
- Disability awareness - to inform communities about the rights, needs, potential and contribution to society of people with disabilities.

At the inaugural DPA meeting Don McKenzie expressed how he saw this as being a crucial role for the DPA.

...The Assembly's architects believe that the self-help philosophy must be fostered; that there is a need to advocate the rights and responsibilities of disabled people in the community... (1983:17).

## **Treaty Partnership**

DPA aims to

- Actively promote Maori (tangata whenua) at every level in DPA - to ensure that solutions to disability-related issues acknowledge the Treaty of Waitangi.

This is a recent inclusion into the DPA action plan and initially was not recognised in the development of the DPA. It should be acknowledged that at that time ‘working within the principles of the Treaty of Waitangi’ did not have the same prominence in social policy in New Zealand as it does today. It can be argued that disabled people were only just beginning to develop an analysis of oppression in society and recognising their own position. The DPA, like other non-government organisations have been challenged by the Maori people to review its organisational structures to encourage greater participation of Maori people in decision-making at all levels – to look at ways to incorporate bicultural approaches. In her interview with me, Anne notes how the DPA has had some difficulties in making real progress in this area, having only conducted one national Hui in 1997 where Maori members appointed a Maori adviser. She points out how they have now got resources that can specifically be used for this purpose, and believes that the appointment of the Maori adviser will also greatly assist in facilitating this process.

### ***International***

DPA maintains

- Effective international links through its affiliation with Rehabilitation International<sup>12</sup> and Disabled Peoples' International.<sup>13</sup>

At the inaugural DPA meeting Byron Buick-Constable stressed the importance for the DPA to maintain international links, warning “insularity breeds superiority and smugness” (1983:14). At that same meeting, Professor Charlotte Floro made the following statement:

every country regardless of size, location and level of development needs this international linkage. Without it approaches to rehabilitation problems would remain static, conservative and even outdated. What is happening in New Zealand this weekend is significant in promoting this international linkage because this is a model of partnership for the world to follow (1983:34).

<sup>12</sup> Rehabilitation International is an organisation largely comprising able-bodied health professionals, service providers and government officials. Its focus is on the provision of rehabilitation services throughout the world, however it has been criticised by Stott (in Beatson, 1988) for working rigidly from a medical model perspective.

<sup>13</sup> Disabled Peoples' International is an organisation solely controlled by disabled people. Its focus is on promoting the rights of disabled people throughout the world, working closely with United Nations organisations.

It is important to note that the role of the DPA is not to directly provide services to disabled people but rather to promote their needs locally, nationally and internationally to communities, governments and service providers (including to their own corporate members). In Chapter seven I discuss some key projects that the DPA was instrumental in establishing, services that are now provided nationwide through private enterprises and have significantly enhanced the lives of many disabled people.

## **Conclusion**

In this chapter I have described the structure of the DPA as a national organisation, outlining a structure which is intended to ensure that the balance of power within the organisation remains with disabled people. I have drawn on papers presented at the inaugural DPA meeting in Hamilton in 1983 to illustrate where the fundamental principles from which the DPA now operates were first formulated. This material communicates the passion and commitment that people such as Quentin Angus, Don McKenzie, John Stott and Byron Buick-Constable brought to their work as they established an organisation that would be recognised as the “speaking voice of the disabled”. It can be argued that they were clearly working for structural change that would bring about real change in the lives of disabled people in New Zealand and internationally.

Within this discussion, issues of who the DPA represents and the potential conflicts of interest that exist between the various categories of membership have been explored. The role the DPA has defined for itself and its working relationship with international organisations, the government, service provider organisations, and individual disabled people and their families was also discussed, reflecting back on the initial ideas of the founding members.

It is from this foundation that I move on in the next chapter to present a brief biographical synopsis of the six people who have held the position of National President of the DPA since its inception. I will also outline key projects undertaken during the terms of each of the Presidents and discuss their leadership styles for these have had a significant influence on the development of the DPA.

## Chapter 6

### *The Six National Presidents of the DPA and their Leadership Styles*

#### Part A

Again, this chapter has two parts. Its overall focus is on leadership in the DPA. Part A consists of biographical sketches of the six National Presidents in terms of their contributions to this organisation. Part B analyses their leadership styles using the frameworks of Devito (1997) and Bass (as cited in Bartol, Martin, Tein & Matthews, 1998).

#### *The Six National Presidents*



**Quentin Edward Angus MBE** was born 1<sup>st</sup> April 1926 and died 15<sup>th</sup> June 1996. He had cerebral palsy, which greatly affected his mobility. Quentin was at home up to 10 years of age (not attending school at all during this time). At age 10 he attended Napier Central primary school, then to St. Marks when his parents shifted to Wellington, and later Wellington College. He went on to attend and complete a law degree at Victoria University, Wellington. After Quentin completed his degree he worked as a law clerk, then as a staff solicitor before becoming a partner in a private law firm in Wellington. He then established a successful legal practice in Otaki. Finally Quentin was Assistant Office Solicitor then Office Solicitor for New Zealand Rail before retiring in 1986.

In the 1970s Quentin became involved in disability issues as a member of a number of committees comprising parents of children with various impairments. He identified a need for greater coordination between disability groups, becoming actively involved in the Wellington Coordinating Council (later to form the New Zealand Council for the Disabled).

Quentin was a key figure in the establishment of the DPA in 1983 (outlined in Chapter 3). He was the President for approximately six months from the inception of DPA until its first AGM on 15 May 1983.

Quentin was committed to the principles of dignity and rights for disabled people. He was able to combine

his legal expertise with his personal experience of disability in pursuit of the best legislative protection and support mechanisms for people with disabilities (Zillwood, August 1996:16).

He was passionate about the need for physical access to buildings and facilities, being instrumental in drafting access standards for codes for public buildings encompassed in the Disabled Persons Community Welfare Act, 1975. Again, in 1985 and 1992 he was involved in the development of the Standard Code of Practice for Design for Access and use of Buildings and Facilities by Disabled People NZS 4121 (1985), the Building Act (1992) and the Human Rights Act which was eventually enacted in 1993. He continued to provide legal advice to the DPA and to be involved in commenting on proposed legislation up until the time he died in 1996. Quentin was awarded the MBE for his services to the disabled in the New Years Honours in 1985.



**Byron Buick-Constable MBE** was born 18<sup>th</sup> April 1945 and died 5<sup>th</sup> November 1988. He had Becker Muscular Dystrophy, and had been in a wheelchair since his late teenage years. Byron and his family were very involved with the Muscular Dystrophy Society for many years, actively advocating for genetic research and promoting the needs of people with Muscular Dystrophy and their families.

Byron was educated in Fiji. He graduated from Victoria University, Wellington with a BA (Honours) in Economics in 1967. From there Byron had a distinguished University career, holding the following positions over the years - Faculty Clerk, Faculty of Commerce & Administration; Deputy Managing Secretary and Managing Secretary of the University Union; Appointments Officer and Assistant Registrar, Information & Publications (which he held up until the time he died).

Byron was the chairman of Rehabilitation International New Zealand in 1981, and was responsible for the overall planning of the IYDP in New Zealand. He was credited as being instrumental in establishing New Zealand as a player on the global rehabilitation scene. During his two terms as President of the DPA he attended two Rehabilitation

International Assemblies, and is recognised as having had significant input in RI reforms whereby the constitution was changed to allow for greater participation by disabled people (Stott cited in Beatson, 1998). Byron was nominated for the position of World President of Rehabilitation International in 1988.

Byron was the first elected President of DPA, a position he held from 1983-1985. Key projects undertaken by the DPA during Byron's term as President included the implementation of a national transport service, Total Mobility, a national information service and Teletext (these projects will be outlined in depth in Chapter 7), as well as encouraging the development of Regional Assemblies and increasing the DPA's membership. Other issues he addressed during this time included employment for disabled people, income levels for disabled people, the need for accommodation options and community living supports.

Byron was awarded the MBE for his services to disabled people in the New Year's Honours, 1988.



**John William Stott QSO** was born 10<sup>th</sup> December 1948 and died 13<sup>th</sup> December 1997. John became a T4 paraplegic as a result of a tramping accident in 1964. At the time of his accident John was in his fifth form year. After his recovery in hospital he returned to Invercargill to complete his schooling.

John explained that he had wanted to enrol in teacher training but the regulations at that time precluded this (Stott cited in Beatson, 1998). Instead he began a New Zealand Certificate in Orthopaedic Technology which he completed in 1970 after which he worked for the Southland Hospital before setting up his own footwear business in 1972. In 1976 John completed Stage 1 of the New Zealand Certificate in Commerce, signalling a change in career.

Between 1977 and 1980 John was the regional secretary for the Labour Party in Southland. During this time he worked with J. B. Munro (who was the MP for Invercargill), and John himself had one term as a city councillor for Invercargill during this time. John commented (Beatson, 1998) that he did not feel comfortable in this political role, and so began a new career as a staff member in local bodies. The positions he held included working in the Invercargill town clerks department, a

manager's position with the Hokitika Borough Council, and then the Banks Peninsula Council as District Manager. In 1993 John took up a position in the Disability Support Services section of the Southern Regional Health Authority, a position he held up to the time he died in 1997.

John became active in the disability community predominantly through sport soon after his accident. He was Secretary, and later President of the Southland Wheelchair Sports Association, and then National President of the New Zealand Paraplegic and Physically Disabled Association. When he was 18 years old John represented New Zealand in a range of sports at the Paralympics in Israel.

Like Byron, John was very involved with the IYDP, chairing the Southland IYDP regional committee. John was not involved in the early planning stages of the DPA. However he was aware of the developments that were occurring, and was very much in favour of the direction being taken. John was elected onto the first DPA National Executive Committee in 1983, and was the National President from 1985-1989. During his term of presidency John focused on consolidating the DPA's position as a credible organisation representing the interests of disabled people and disability-related organisations in New Zealand. This also involved addressing the need for the DPA to financially sustain its activities to secure its existence in the future.

The pinnacle of John's career was his appointment as the World President of Rehabilitation International in 1992, a position he held for four years. John discussed how in this role he was able to facilitate the restructuring of Rehabilitation International, and to promote the needs of disabled people in an international forum (Beatson, 1998).

John was awarded The Queen's Service Order for Community Services in 1994.



**Marilyn Baikie** was born 5<sup>th</sup> March 1949. Marilyn became a paraplegic as a result of an accident in 1967 when she was part way through teacher training. She discussed how there was quite a battle for her behind the scenes to be able to continue her teacher training, describing considerable resistance from the 'education hierarchy' who were against disabled people becoming teachers. Marilyn says she was informed many years

later that teaching staff at the Teachers' Training College advocated on her behalf for

her to complete her training. She did go on to complete her Bachelor of Arts degree and a Diploma in Teaching, and began a successful career as a primary school teacher. Marilyn took a short break from teaching to have her two children. Today Marilyn works as a senior teacher at a primary school in Christchurch.

Marilyn recalled that soon after her accident she became involved at the local level of the New Zealand Paraplegic and Physically Disabled Association, where she helped to raise funds for a hostel at the Christchurch Spinal Unit. She withdrew from this Association when she married and started her family. Marilyn had no further contact with the disability community until she joined the DPA in 1984, first becoming involved as a committee member for the Christchurch Regional Assembly. She recalls that the Christchurch Regional Assembly had only recently formed at that stage. Not long after she joined the DPA Marilyn was elected onto the National Executive Committee.

Marilyn's term of presidency was from 1989-1993. The early phase of her term as President was difficult as the Chief Executive Officer at that time, Ken Munro, had died suddenly. Marilyn had to adjust to her new leadership role and bring on board the new Chief Executive Officer, Dave Henderson. She recalls her approach to the presidency as maintaining "business as usual", making submissions and lobbying for the rights and needs of disabled people. Early in her term as President Marilyn facilitated a process to develop the first Policy Book for the organisation. A major project at this time was the campaign to have 'disability' in the Human Rights legislation (which included developing alliances with other marginalised groups). Another focus was on employment needs of disabled people with the DPA working with government and other groups to develop strategies that would create real job opportunities.

Like her two predecessors, Marilyn was also very active in the international scene. Marilyn was the Oceania vice-chairman for the Asian Pacific Region of the Disabled Peoples' International. In 1993 Marilyn received international acknowledgment for her work when she was presented with a personal award from the DPI for her distinguished service in the related fields of disabilities and rehabilitation. Another international highlight for Marilyn was the leading of a successful delegation to the Rehabilitation International Congress in Nairobi to bid for New Zealand to host the 1996 Congress.



**Anne Hawker** was born 1<sup>st</sup> August 1951. Originally from Australia, Anne came to New Zealand in 1976. As a young mother Anne was diagnosed with Multiple Sclerosis. She became active in the Multiple Sclerosis Society soon after her diagnosis, and from there she became involved in disability issues.

Anne graduated from the University of New South Wales with a Bachelor of Commerce (Honours) and a Diploma in Education. Later in New Zealand she completed four papers towards a Certificate in Rehabilitation Studies.

In 1974 Anne began a career in teaching. With the onset of multiple sclerosis Anne changed direction in her career, working at the Mosgiel Disability Resource Centre from 1980-1989, with her roles including being the Coordinator of the Attendant Care programme. From 1990-1994 she worked as a private consultant, undertaking projects such as a research, establishing two home support services, and working as an accommodation broker. Other positions Anne has held include Chief Executive Officer of the Head Injury Society and Central Health Manager in the Disability Support Services. Anne is currently working for the Accident Compensation Corporation as the National Manager of Rehabilitation Services.

Anne joined the DPA in 1984. Her term of National Presidency was from 1993 to 1997. During this time Anne facilitated the progress of a number of projects. These included the review of the DPA policies that resulted in the production of the second Policy Manual (published in 1995) and the implementation of an annual strategic planning process for the National Executive Committee. Under Anne's leadership a subsidiary company called Maxeq was established to try and form a more stable financial base for the organisation (outlined in Chapter 5). Training packages for regional assemblies such as packages to raise awareness amongst disabled people about their rights under the Human Rights Act 1993 were also developed and implemented. Another significant achievement at this time was the successful campaign for a question on disability to be included in the 1996 Census, with a follow-up survey being conducted to gather qualitative and quantitative data. The pinnacle of her term as President was the opportunity for the DPA to host the 18<sup>th</sup> Rehabilitation International Congress in Auckland in 1996.

Anne continued as a committee member of the National Executive Committee after retiring as President until retiring completely from the National Executive Committee in 1999.



**Paul Gibson** was born 23<sup>rd</sup> September 1961. He describes himself as being legally blind, although he has some useful vision.

Paul was raised in Taranaki. He was mainstreamed through his primary and secondary schooling. When Paul first left school he began farming in Taranaki, however his deteriorating eyesight necessitated a change in direction, so he began his studies at Victoria University, Wellington. Paul has a Bachelor of Science (physics), and is currently studying for a Masters in Public Policy with a research focus on disability and poverty. Paul is very involved in student politics at the University, having been part of a group that established Campus Abilities and the Disabilities Organisation “Can-Do”, which is a support group for disabled students. He has also been President and Chief Executive Officer of the Victoria University of Wellington Students Association, and a Victoria University Council member. Paul established the Tertiary Students with Disabilities annual conference and has been active in a group known as “Achieve” – the National Post-Secondary Education Disability Network, working briefly as Chief Executive Officer. Paul is currently a member of a consumer panel for “Inside Out” a television series focusing on disability issues.

Paul has not been a member of the DPA for very long. He learnt about the organisation through his activities at the University, joining the DPA in 1992. Paul was elected as the National President in 1997 – a position he still holds today. Projects undertaken during his term include holding a national Hui on Maori and disability, and the development and promotion of a manifesto document ‘Our Vision’. Campaigns undertaken by the DPA under Paul’s leadership include ensuring that Government continues to develop strategies for government departments to comply with requirements within the Human Rights Act and campaigning against the introduction of Work Capacity testing and other related changes to Income Support policies.

## Part B

### *Approaches to the Leadership Role in the DPA*

#### **Distinguishing Between Management and Leadership**

In order to understand the role of the leader in any organisation it is important to be clear about the distinction made between management and leadership. Management is the process for achieving organisational goals (Bartol, Martin, Tein, & Matthews, 1998). Cohen (1990) defines leadership as the art of influencing others to their maximum performance to accomplish any task, objective or project. It is about being able to win the minds of the people, and being able to motivate them. In the DPA, the management role is taken by the Chief Executive Officer while the leadership role is that of the National President. An examination of leadership styles within the DPA is included as it can be argued that these have had a significant influence on the direction of the organisation.

#### ***Leadership***

Cohen (1990) argues that leaders are made not born and that in order to be successful they must develop the necessary skills. Burton & Dimpleby (1995) expand this further, arguing that successful leadership is dependent on several variables. These include the leaders personality and behaviour, the composition and function of the group, the social context, the structure of the group, the nature of the task, and whether the leader can be described as effective or ineffective in mobilising the group and completing the initial objectives.

#### ***Leadership Styles***

Having defined what leadership is, it is useful to examine leadership styles. Devito (1997) provides a framework that outlines three distinct styles of leadership. In identifying leadership styles he discusses the possible impact on a group and its ability to achieve goals when led by someone with the respective leadership style.

The first style he discusses is that of a laissez-faire leader. This type of leader takes no initiative in directing or suggesting alternative courses of action, rather, they allow the group to develop and progress on its own, even allowing it to make its own mistakes.

Such a leader denies having any real authority, or gives up authority they do have. They answer questions and give information to group members, but only when specifically asked. Such a leader does not give any form of reinforcement, however the advantage of such a leader is that they are seen as being non-threatening. Generally this type of leadership results in group members feeling satisfied about participating, but the group may be inefficient.

The authoritarian leadership style is the opposite of the laissez-faire leader, whereby the leader determines group policies and makes decisions without consulting or securing agreement from the members. Such a leader tends to be impersonal. Group communication is expected to go through the leader, not between group members, thus enhancing the leader's importance and control. If the leader is competent the group may appear to be highly efficient, but not likely to feel satisfied about their involvement in the group.

The final style of leadership Devito identifies is that of the democratic leader. A democratic leader provides direction while still allowing the group to develop and progress the way its members wish and encourages group members to determine their own goals and procedures. A democratic leader is able to support self-direction and self-actualisation of members, giving them reinforcement for the achievements made, and making suggestions for future direction and alternative courses of action. This form of leadership results in both satisfaction of group members and overall group efficiency.

In summary, the authoritarian leader takes most of the control and responsibility for both the group process and its outcomes while the laissez-faire leader assumes little personal control. The laissez-faire leader passes over control and responsibility of the group processes and its outcomes to the group members. The democratic leader takes some control and responsibility for group processes and outcomes, but also ensures the members know they are active participants in the group. Devito concludes that when all group members are equal in their knowledge and are concerned with their individual rights, having a democratic leader is likely to be most effective for the group.

Bass and his colleagues present another framework from which to examine leadership that makes the distinction between transactional leaders and transformational leaders (cited in Bartol, Martin, Tein, & Matthews 1998). They describe transactional leaders as those who motivate others to perform at expected levels by helping them recognize tasks that need to be completed, to identify goals and to acquire confidence in being

able to meet desired performance levels. Transactional leaders help people to understand how their needs and the rewards they desire can be linked to goal achievement. Transformational leaders are seen to be able to motivate people to perform beyond normal expectations by inspiring them to focus on broader missions. They encourage people to rise above their own immediate self-interests and to concentrate on higher-level goals, rather than focusing just on lower-level goals such as safety and security, and to believe in their abilities to achieve these missions (cited in Bartol, Martin, Tein, & Matthews 1998).

### ***Leadership Styles Reflected in the DPA***

In my research for this thesis I asked the participants to identify what they thought was their (or that of their spouses) style of leadership, and then to discuss how they thought others saw their leadership style [see Appendix 1]. This section will examine their responses and analyse their leadership style using the frameworks from Devito (1997) and Bass (cited in Bartol, Martin, Tein, & Matthews 1998) outlined above.

### ***Quentin***

In her interview Pauline Angus spoke of Quentin's reluctance to be in the limelight... that he saw himself as being "the back-room boy". However, she recalled times when Quentin took on the role of leader, especially when he felt there was an important issue to pursue. She related a situation at an international forum where other disabled people looked to Quentin to be the leader in ensuring a point was followed through<sup>14</sup>. Pauline felt that some people saw Quentin as being pig-headed and sometimes inflexible, but that he was also seen as being extremely skilled and knowledgeable. She observed how Quentin seemed to polarise people, they either liked him or they didn't! Gregory (1995) discusses how Quentin was able to work with others to impassion them with the vision he was working towards, which are qualities that Bass identifies in transformational leaders. In relating Quentin's leadership style to the categories outlined by Devito above, he displayed characteristics of both a democratic and an autocratic leader, depending on the situation. It is clear that he worked with others who shared a similar

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<sup>14</sup> The incident was at the Rehabilitation International Congress in Vienna in 1986. Pauline recalled how people quickly gravitated around Quentin as he was wording a motion to be put to the congress that called for disabled people to be able to participate with dignity fully in all aspects of everyday living. There was considerable difficulty in having the motion recorded completely the way disabled people were proposing it... that the word 'dignity' was dropped off several times. Quentin persisted until eventually the motion was put in its correct form.

vision to him and were impressed with his skills, and were therefore prepared to work with him to achieve the ultimate goal of establishing the DPA.

### **Byron**

Byron Buick-Constable was seen as someone who “led by example”<sup>15</sup>. He is remembered for his determination. This was apparent in his work to achieve access for disabled people to facilities and buildings. In their interview Mary and Lindsay Buick-Constable reflected how he broke new ground with his appointment as Assistant Registrar of Information and Publications at Victoria University, Wellington. However they noted that:

*Nobody... does all these things on their own... You have to convince other people in the organisation that something's possible and then work on it...*

*He was able to persuade them that it was in their own immediate and future interest... he had the inspirational ability to do that.*

This illustrates the points made by Cohen (1990) that it is important to be able to motivate people to work towards achieving identified goals. It appears Byron combined the rational approach of his background in economics with his belief for the need for change to get people on board to achieve his goals.

### **John**

John is remembered as being a strong leader. In her interview Mary Stott had this to say about his leadership.

*I liked watching him... he was very direct with what he wanted to do. He always had the big picture. He always felt like he was the conductor, you know, organising the orchestra. He usually had... a fixed idea about what he wanted to do, but he was willing to change if people thought another way was better. He was never particularly worried about how the path went unless it got way off line. So long as the end result was what he was looking for or what he felt should have been the best result.*

In an interview with Peter Beatson, John had this to say about the way he preferred to work.

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<sup>15</sup> Information on Byron's leadership style was obtained from his parents in their interview, and from archival material.

I didn't take a radical stance because I preferred to work alongside people rather than against them. It took longer, perhaps, but you achieved more. Through a process of negotiation, over time people gained a better awareness of what was required.

Eventually you might have to confront them head-on, but by that stage you had developed a rapport and could afford to be a bit more challenging. Being patient is more effective than attacking people in the very first conversation... You have to be a little circumspect! Eventually they understand what you want, why you want it, and become allies rather than adversaries (1998:6).

Like his predecessors, John approached his work as National President of the DPA with a clear vision of what he wanted to achieve. He was prepared to work alongside people to ensure the organisation reached its goals. For John, the process was as important as achieving the goal itself. Therefore I believe John was committed to working as a democratic leader.

### **Marilyn**

In her interview with me, Marilyn Baikie recalled that at the time she became National President of the DPA she had no particular aspirations or plans she wanted to achieve. She was urged by John Stott to take on the role as he felt there was nobody else around to pass it onto.

*I don't think I really went in with any huge aspirations or hopes or plans. Because I didn't work in the disabilities field I don't think I really went in there thinking this is what I want to change so much as I felt it was really important for people with disabilities to be empowered and to have control over their lives...*

Marilyn translated her commitment to the process of empowerment into her role as the National President. She identified that she worked very much from a consensus approach.

*...Because I always felt I didn't have a huge knowledge of the whole disability environment really because I didn't work in it. And I guess I came in as president more as someone who could listen to all the other people on the Executive, perhaps, and try and get some sort of consensus from them rather than trying to push my own barrow because I really didn't have one to push...*

*...I guess I came in almost as a chairperson or a president who may have come in from, who had no interest perhaps in the whole disability field but was able to chair a meeting and, you know, bring the best out of other people. I hope that's what I was able to do.*

Her emphasis was to make sure that Executive meetings flowed, that people were not allowed to 'waffle' and get off the point. However, I believe that by working with no particular plan of what she wanted to achieve during her presidency, Marilyn could be seen to be more of a laissez-faire leader at times rather than the democratic leader she was striving to be. It seems there may have been times when Marilyn looked towards others on the National Executive and the wider DPA membership for direction. This by no means detracts from the achievements during her presidency. Her style enabled her to feel confident in delegating responsibility to other Executive Committee members and encouraged greater input from the wider membership.

### **Anne**

Anne took on the role of National President of the DPA with some clear ideas of what she wanted to achieve. She was determined to have input into social and political change that would make a difference in the lives of people with disabilities. In her interview Anne explained how she tried to work in a consultative way where possible, aiming to use the skills of everyone in the group. For Anne

*...it was a style that had a clarity of purpose, a plan which everyone knew about, a straight-out strategic plan. For me my role was that of a facilitator. And probably there was a certain amount of role modeling... I did a reasonable amount of work. And to me it was a leadership style that showed that DPA was a professional organisation... It was a leadership style that encouraged an arena of debate but I would not ever tolerate attacks personally on people.*

Anne said she made a point of involving others in the running of meetings. She used to get her Vice-President to run sections of the meeting and to plan agendas for those meetings. Anne also looked towards Marilyn (as the immediate Past-President) for support. She believed if she had not incorporated those people, the role of President would have been a very lonely one.

At a philosophical level Anne was committed to a democratic style of leadership. She was clear though that the consultative approach was not always possible because of

tight timeframes they were working to, where decisions often needed to be made quickly. However, Anne also stated she expected loyalty to herself from the people working closely with her and believed that open debate should occur in the committee room. She felt frustrated when she discovered situations where people did not speak in the committee forum, instead choosing to criticise her outside the meeting. Anne stated she had little to say when she was President as she was concentrating on facilitating the input of others. She felt it was important that other people contributed their ideas.

Anne concluded that for her, leadership is based on mutual respect.

*Mutual respect for the respective roles that everyone plays and that people are here... that people come from such diverse backgrounds... and to say to people that [their] diverse background is what makes your contribution important... You have some strong people [it is important] to get them to respect that every person has a right to have a say.*

### **Paul**

Paul took on the role of National President of the DPA with limited prior experience of the organisation. His only contact with the DPA had been through the student group at Victoria University, Wellington. In his interview he explained that he had intended standing for the National Executive Committee, but like Marilyn, was 'approached' to stand for president. However, he went into the position with some clear ideas about what he wanted to achieve.

Paul felt the organisation had tended to focus a great deal on issues related to disability support services and he wanted to put more attention into other areas such as education and employment. He also felt people other than those with physical impairments were underrepresented in the National Executive Committee, that the committee did not represent the cross-section of disability. His main goal was to make the Executive more representative, and make the way the committee handles issues and sets priorities more reflective of that cross-disability perspective. He was keen to raise the profile of the DPA in the community.

When asked to identify his leadership style, Paul said he did not know if he worked to one. However, he felt he took a facilitative approach and that he felt uncomfortable leading from the front. He explained:

*I believe I've got a lot of skills to contribute and knowledge to contribute but I'm not the only one and there are others who have more to contribute... [The job] I believe is to be able to fuse all those contributions, to maximise them all, to put them all together in a coherent way.*

Paul felt it was important to keep looking ahead at the “big picture”.

*I try and keep looking ahead to the bigger picture, the vision of what DPA should be doing longer term, what we're about, where we're going rather than getting buried in the here and now.*

He saw himself as being reasonably laid back in the approach he used when chairing meetings. He explains:

*I try and let people establish the ground rules. And that might be seen as being too... directionless, people are looking for a specific direction, but I try and make sure there still is a direction. If the group doesn't come to a consensus, it's somebody's role to try and point it somewhere and then the group can say 'no'... And with that I have to respect the experience of everyone else in DPA. In the Executive many of them just have more years involvement in whatever they're doing and I do respect that.*

*... I want people to feel that respect and feel that they have more to contribute in an area than what I have.*

Paul's approach to his role at present suggests that of a predominantly laissez-faire leader. While he is committed to encouraging maximum participation from others on the Executive and from the wider DPA membership he appeared reluctant to take direct control of the process. While he took over the role of Presidency with some clear ideas about what he wanted to achieve he seemed reluctant to openly set the direction for these outcomes. However, it should be recognised that at the time of this interview he had not been in the position for long and did not have the benefit of long-term involvement with the DPA.

## **Conclusion**

The six individuals who held the position of National President of the DPA since its inception in 1983 had distinct leadership qualities and brought considerable talent, skills and knowledge to the organisation. All except John Stott came from a background of

higher education. They are all recognised as being highly successful in their careers and other community positions they held. All except Quentin Angus (whose impairment was congenital) experienced the onset and/or deterioration of impairment later in their lives. I believe this is significant as they all had a strong sense of what impeded their ability to function and participate fully in society, that it was not their impairments but rather the physical, social, attitudinal and political barriers confronted by disabled people daily. They all worked from a strong sense of social justice and were committed to working for change.

The early leaders, Quentin Angus, Byron Buick-Constable and John Stott were driven by the vision to establish the DPA as a strong organisation representing disabled people and their families, service providers, and consumer groups. There were high-profile projects to provide the momentum, and people were excited about this new organisation that was seen to be radical in what it was setting out to do. The whole thrust in the early days was for innovation.

As the DPA became more established, the emphasis from the later Presidents was for the consolidation of organisational structures and processes and its work in the wider community. It was becoming more difficult to identify people with the necessary drive and skills to take on the leadership role in an organisation with such a diverse membership that was rapidly growing in size. Marilyn and Paul were both 'approached' to stand for President as it was felt there was no one around who was willing and able to take on the role. Marilyn had no specific ideas about what she wanted to achieve and therefore focused on facilitating processes within the DPA to ensure the organisation met its goals. Paul had clear ideas about what he wanted to achieve but seemed overawed with the magnitude of the task, and with what he perceived as the calibre of people in the organisation.

This analysis of the leaders and their leadership styles has provided greater insight into these individuals personal qualities and attributes, and their achievements. Each President was able to effectively motivate people and influence them to work to their maximum performance, accomplishing a range of projects, which discussion in chapter seven will show, significantly impacted on the lives of disabled people. This examination of leadership styles within the DPA provides a good illustration as to how leaders can have a significant influence on the direction of the organisation. This discussion provides a base from which to examine some of the achievements of the

DPA, phases of its development and issues that will need to be addressed if it is to continue to have a leading role in the disability movement in New Zealand.

## Chapter 7

### *Successes and Ongoing Issues for the DPA as Part of the New Zealand Disability Movement*

#### **The DPA as an Organisation**

It can be argued that the DPA provided a focal point for the disability movement in New Zealand, facilitating the mobilisation of disabled people in an organised way to promote their needs and advocate for change. Significantly, the impetus for this movement was not coming from service providers and professionals in the disability field. People with a range of impairments were setting the agenda. The establishment of the DPA provided both a focal point and an organisational structure for the disability movement in New Zealand. This chapter analyses the development of the DPA as an organisation using a model on organisational life cycles.

While the DPA provided a focal point for the disability movement and challenged the marginalised position of disabled people, it was also trying to establish itself as an organisation. The early leaders were aware that the organisation needed to develop a nationwide structure to coordinate its activities while at the same time developing a secure funding base in order to function. Don McKenzie highlighted these stressors in his address at the inaugural AGM.

The difficulties we currently face include: assured funding; sound representation from a wide cross-section of administrators, professionals and disabled people; and a nationwide coverage through the establishment of regional assemblies. Whilst these logistic matters are being sorted out, the pressing fundamental needs of disabled people go on crying out for satisfaction... (McKenzie, 1983:18).

Oliver and Zarb warn of the difficulty organisations like the DPA encounter as they establish themselves and work for change, observing how:

The disability movement is located at the periphery of the traditional political system, that is, their relationship to the State is not the same as those of organisations for the disabled in terms of consultation procedures, lobbying and accessing resources (Oliver & Zarb, 1997:204).

They further argue that:

The disability movement must develop a relationship with the State so that it can secure proper resources and play a role in changing social policy and professional practice. On the other hand, it must remain independent of the State to ensure that the changes that take place do not ultimately reflect the establishment view and reproduce paternalistic and dependency-creating services, but are based upon changing, and dynamic conceptions of disability as articulated by disabled people themselves (Oliver & Zarb, 1997:211).

This has been an ongoing conflict for the DPA. While the organisation has always had close contact with politicians (see Chapter 5), it has often struggled to access adequate funding on an on-going basis to sustain its activities. In Chapter five I discussed how the changes made in 1989 to the way in which organisations accessed government funding meant the DPA was required to contract with government departments to provide specific services. The terms are clearly dictated to the DPA as to the level of monitoring and advice the Government requires, making it difficult for the organisation to maintain its role of challenging the marginalised position of disabled people in New Zealand.

In order to understand the effect of the two sets of pressures the DPA faced, it is helpful to examine the organisational development of the DPA.

## **Organisational Life Cycles**

In her discussion on social movements Jane Campbell suggests:

The transition from emerging to emergent movement is signified when the movement becomes larger, less spontaneous, better organised, and led by formal structures rather than ad hoc committees and informal groups (Campbell, 1997: 86).

This is consistent with the development of the DPA as an organisation. We can analyse the DPA's development using a model of organisational development outlined by Bartol, Martin, Tein, & Matthews (1998), that identifies challenges faced at each stage, and discusses strategies that need to be implemented if the organisation is to survive in the long term.

This model outlines predictable stages of development that organisations pass through – the entrepreneurial stage, the collectivity stage, the formalisation and control stage, and the elaboration-of-structure stage (Bartol, Martin, Tein, & Matthews, 1998). It argues

that progress through each stage requires specific changes in operating methods in order for the organisation to survive and grow. The model emphasises how as well as making these specific operational changes it is essential that managers and leaders plan for and encourage further innovation in order for the organisation to be successful.

The following discussion gives a brief overview of the organisational life cycle, which is related to the development of the DPA. Responses from the DPA and its leadership to the challenges presented at each stage are examined. As part of this discussion I will outline three key projects undertaken by the DPA at different stages of the organisation's life that were crucial in the overall development of the DPA and helped to establish its credibility in the disability community and the wider political arena.

### ***One: Entrepreneurial Stage***

It can be argued that major innovation is the foundation of a new organisation. This innovation is often based on a single individual's initiative and the organisation may be perceived as a one-person-show. This stage is likened to the infancy stage in human development, and is a time of great creativity. However, as the organisation is in its infancy, (Bartol, Martin, Tein, & Matthews, 1998) little planning and coordination occurs. Work progresses, but the need for resources eventually causes a crisis, with many organisations failing within the first five years. The leaders of organisations in this first phase tend to adopt an entrepreneurial approach, usually showing a great deal of excitement, enthusiasm and creativity in their role (Bartol, Martin, Tein, & Matthews, 1998).

In Chapters four, five and six I discussed how the period leading to the establishment of the DPA and the first 2-3 years of its existence was indeed a time of significant innovation. However, it does not appear that the organisation was run as a one-person-show. Clearly the initiative for encouraging the Rehabilitation International New Zealand, the New Zealand Council of the Disabled and those interested in forming a branch of the Disabled Peoples' International in New Zealand to merge and form the DPA came from a small group of enthusiastic individuals.

In its early years the DPA experienced significant growth which was coupled with increased expectations from disabled people about what could be achieved. In his address at the second AGM in 1984 Byron Buick-Constable (1984) reported that the DPA had 550 members – comprised of both individual and corporate members. In 1985

he further reported that the membership had doubled to 1100 (276 corporate members and 824 individual members).

John Stott's report to the 1984 AGM emphasised the need for regional assemblies in order to establish "grassroots, bottom-up" networks that could respond to local issues and individual needs, as well as providing a communications network to gather data for lobbying and making submissions to Government.

John also noted that the establishment of regional assemblies provided opportunities for people to develop leadership skills. He concluded his report with an announcement that one Regional Assembly had been formed, with another eleven regions working through the process to be formally recognised. A year later Buick-Constable (1985) announced that the DPA had 24 Regional Assemblies that covered 90% of the country.

During this entrepreneurial stage the DPA successfully undertook a number of high profile projects that had significant impact on the wider disability community in New Zealand. Two key projects that I will briefly outline, Total Mobility and Teletext, were completed within the first ten years of the organisation's life. As the following overview shows, through these projects the DPA was able to address crucial needs in the areas of transport and access to information for disabled people while exploring new ways of working within existing systems. The success of both projects has provided a base from which the DPA can continue to campaign for further initiatives in these and other areas, and has helped bring its diverse membership together to work on key issues common to all disabled people, regardless of their particular impairment.

### **Total Mobility**

In 1981 a nationwide 24-hour Telethon was held to raise funds to benefit disabled people in New Zealand as part of the IYDP (outlined in Chapter 4). A report to the inaugural DPA AGM from J. B. Munro (1983) stated that the Telethon raised \$7,000,000. He explained that a significant number of the applications (valued at \$2,750,000) from organisations (including service clubs) to the Telethon Trust were for assistance with transport, demonstrating a huge need for an accessible transport service available 24 hours a day, 7 days a week nationwide. The Trust decided it was not appropriate to give money to all these groups, as it would not be addressing the real problems. Instead it resolved to promote the development of an integrated transport service that would be accessible, affordable and available on a demand/response basis to

disabled people throughout the country (Munro, 1983). A grant to establish a service was given to Rehabilitation International New Zealand which was then signed over when RINZ merged in the forming of the DPA.

Total Mobility was established by the DPA in conjunction with the New Zealand Taxi Proprietors Federation with funding from the Urban Transport Council. Mini-vans were purchased that were then modified, with wheelchair hoists being fitted. The vehicles could also be used for non-disabled passengers making the operation of the service economically viable. J. B. Munro (1983) argued that it was necessary to ensure the vehicles were fully utilised, urging organisations such as the IHC and the CCS to stop running wheelchair accessible vehicles and instead support Total Mobility. A training programme was implemented for taxi drivers to be aware of the needs of disabled people.

In November 1983 the DPA appointed its first Executive Officer (transport) to work in the National Secretariat to administer Total Mobility, and negotiate with the Urban Transport Councils for funding for each region. A report to the AGM in 1984 (DPA Conference Reports, 1984) outlined the progress that had been made, with meetings having been held in a number of regions to promote the concept. The scheme grew rapidly throughout the country. In 1985 it was reported that there were 29 modified vehicles in operation in nine metropolitan areas from Auckland to Invercargill (DPA Conference Reports, 1985), and in 1988 it was stated that 40,000 trips per month were being subsidised nationwide through the scheme (DPA Conference Reports, 1988). By 1991 every major urban centre and many of the smaller centres had Total Mobility (DPA Annual Report, 1991).

The DPA had clearly stated in its constitution that it was not a service provider and was therefore committed to passing the Total Mobility scheme to an existing service. It had successfully piloted Total Mobility showing that it was a viable enterprise for the transport industry and began devolving the administration of Total Mobility to local and regional authorities in 1987 (DPA Conference Reports, 1987), ceasing its involvement in the day-to-day administration of the scheme by 1990.

The focus for the DPA changed to providing information and advice to the regional councils, Transit New Zealand (formerly the Urban Transport Council) and the Ministry of Transport on the wider issues pertaining to transport needs for disabled people (Annual Report, 1 July 1993 – 30 June 1994). Initially disabled people were entitled to

25% fare discounts if they held vouchers issued by the DPA, however by 1994 people were able to have 50% discounts in all but one region, with subsidies being funded by regional authorities. A number of disability-related service providers now distribute the vouchers.

This project was successful in challenging the view that services for disabled people could only be provided by people who specialised in working in the disability sector. It is clear by the rapid nationwide growth in the service that it did indeed address an urgent need for many disabled people. The lack of an accessible and affordable transport system meant that many disabled people were largely isolated from their communities, limiting opportunities for employment, education, leisure and recreational activities.

### **Teletext**

Another project that originated from the IYDP was Teletext. Teletext is a twofold system providing captioning of television programmes for deaf and hearing-impaired people as well as providing a text-based information and news system accessible via television.

At the inaugural AGM J. B. Munro (1983) explained that RINZ had identified a need for a comprehensive national information system that would be accessible to disabled people and had approached Television New Zealand to establish Teletext. Television New Zealand indicated a willingness to be involved but said they did not have the finances for the project so RINZ applied to the Telethon Trust. As with Total Mobility, RINZ passed the grant received from the Telethon Trust onto the DPA to establish teletext.

In 1983 some television programmes imported from overseas had already been captioned. These captions could be easily accessed if people had an encoder, as could the teletext information pages. RINZ negotiated with an electrical firm, Philips, to import televisions with the required encoders. The televisions were then bought by Group Rentals who rented the sets at a reduced rate to “bona fide individuals and organisations” (Munro, 1983:28), that is, disabled people and disability-related organisations. It was seen to be necessary to establish this interim process as television manufacturers in New Zealand needed time to “get up to speed” in changing components for the new requirements. It was estimated that by 1985 10,000 TV teletext

sets had been purchased throughout New Zealand (DPA Conference Reports, 1985). The response was not as good as was expected so Philips distributed the remaining 200 sets through other retail outlets, thus the discounts for disabled people and related organisations were lost. However, in 1986 it was reported that an estimated 30,000 TV sets had been purchased (DPA Conference Reports, 1986).

Reports show that the number of hours of captioned programmes available was slow to increase, with an average of four to six hours in 1985 (DPA Conference Reports, 1985), increasing to just ten hours in 1986 (DPA Conference Reports, 1986). Progress on the development of the information and news pages was more significant. In the original contract with Television New Zealand 50% of all teletext pages were dedicated to disability-related information. J. B. Munro outlined the policy to be adopted whereby

... each organisation serving the disabled will be allocated a page and a series of sub-pages so that it can transmit its own information. It means that the combined societies for the deaf for instance may well decide to put out a newsletter on TV... (1983:29).

The teletext network went on air on 1 February 1984. In 1985 it was reported that

DPA was contributing to half of the teletext information with news, what's happening, and information updates and future activities (DPA Conference Reports, 1985:21).

The DPA collated information from its member organisations and individuals throughout the country. This information was then forwarded to Television New Zealand staff in Dunedin to be formatted and entered onto the teletext pages. However, there were reports indicating that there were some difficulties in getting information updated in a timely fashion (DPA Conference Reports, 1986).

The contract between the DPA and Television New Zealand expired in 1989. It was not renewed; instead Television New Zealand took full responsibility for the ongoing administration of Teletext. The focus of the DPA changed to advocacy on the wider issues of information accessibility. It was noted that

the DPA was instrumental in encouraging the Broadcasting Commission to allocate funding for both new equipment to improve the captioning service on teletext and to support the production of “News Review”<sup>16</sup> (DPA Annual Report, 1990:1).

As the teletext system evolved it became apparent that there was a need for a comprehensive National Information Service, including information on equipment, and as a result the DPA focus changed. In 1987 a meeting was held with a number of information provider services including the National Library Service, Disability Information Officers and the New Zealand Computer Society to develop terms of reference and a management structure for a National Information Service. It was agreed that if any funds remaining from teletext the DPA would pass these on to the new service (DPA Conference Reports, 1988). The DPA convenor of the Information and Teletext portfolio stressed the need for information providers and disability organisations to work together if the proposed service was to be successful. In 1991 the New Zealand Disabilities Resource Centre in Palmerston North established a national freephone service where people could access a wide range of information. A network of autonomous Independent Living Centres/Disability Information & Resource Centres were established throughout the country.

The teletext project was regarded as a success as it clearly put the need for ready access to information, particularly for deaf people, on the political agenda. The DPA saw the need for access to information as being crucial as it was recognised that ‘information is power’. For disabled people to access information meant they were able to make informed decisions and to access services and resources. The ability to access information (and not just that which is disability-related) from home was revolutionary for many disabled people, especially if they were not able to easily use the telephone.

### **Other Issues**

There were calls from the membership to address a number of other issues. At the 1984 AGM two workshops with the theme “Change through DPA” were held (Darracott, 1984). These sessions addressed two questions – 1) What changes are required? and 2) How can DPA promote these changes? The report outlined fourteen areas listed in priority order as identified by the participants (Darracott, 1984). As well as issues

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<sup>16</sup> “News Review” was a news programme for deaf people shown weekdays and used both captioning and New Zealand Sign Language.

around transport and information, other issues included inadequate incomes for disabled people; the need for public awareness and education on disability; access to buildings and places; lack of employment and education opportunities; and the lack of accommodation options and opportunities for independent living in the community. These expectations reflected both the excitement and the sense of urgency of many disabled people that the DPA could achieve real change. However, it also placed a great deal of pressure on this fledgling organisation and its leaders, facilitating the need for more formal structures and procedures if it was to continue to grow and develop.

### ***Two: Collectivity Stage***

At this stage the organisation is likened to being in its youth. Others who share a strong belief in the goals of the organisation join the entrepreneurial leaders who were in the organisation from the beginning. The membership displays strong feelings of group identification and a sense of purpose in the organisation, with a high commitment to its mission and goals. Structures and communication patterns begin to form, but still tend to be quite informal. During this phase there is usually a strong emphasis on having group members being involved in major decisions. The organisation may experience a crisis when it experiences rapid growth and the existing informal structures can no longer provide adequate direction and control (Bartol, Martin, Tein, & Matthews, 1998).

As noted earlier, the DPA experienced rapid growth in its membership, both in the numbers and the coverage it achieved throughout the country through its regional assembly structures. By 1985 it was recognised that its membership was diverse, and therefore the organisation needed to establish systems that would enable people to actively participate, while recognising the need to accommodate differences. In his foreword John Stott noted how

the character of this Assembly has been different to our previous two. We have learned to become more comfortable with difference – differences in attitudes, in disability categories and in roles that individuals and organisations undertake in our interests.

We have recognised the strength that each other have and the value in working together in common cause. We have been able to face common issues together and come to practical solutions and sound policies.

These are the signs of a maturing organisation, one that is facing the future with a sound philosophical base... (Stott, 1985:1).

John also noted that the DPA was beginning to formalise its structures and processes with the introduction of a clear policy statement, statement of purpose and sound operational principles from which to organise its work.

John was elected as National President at the third AGM in 1985. He outlined his desire to work with the support of the membership, emphasising how

... at this stage it is essential to build on DPA's present position by extending the 'community of interest' network to increase participation and to develop a strong link with the Homebound<sup>17</sup>. A much higher profile of DPA is envisaged to give greater credibility, both at the National and local levels, to the speaking voice of the Disabled (Stott, 1985:1).

This commitment to work with the membership was reflected in the way the AGMs and conferences were structured. The two forums were held in conjunction with each other over a two-day period. Day one consisted of plenary sessions and workshops where a range of topics was canvassed. The National Executive Committee used information and issues from these workshops to set priorities for the organisation during the subsequent year.

These annual meetings were held in different regions each year, and the need to identify resources to enable disabled people to attend these gatherings was regularly emphasised. The DPA responded to this by developing ways of involving people in these meetings who could not attend. In 1986 postal voting for the National Executive Committee was introduced.

It was at that meeting too that the use of telecommunications technology was introduced with people being able to access speeches at home via teletext. The formatting of material related to these annual conferences also reflected the organisation's commitment to ensuring disabled people were kept informed. Prior to the meetings booklets that contained reports from the various portfolio holders in the National Executive Committee were widely distributed. After the meetings Conference Proceedings booklets that contained full speeches (including those from invited

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<sup>17</sup> The Homebound were defined as those whose disability prevents him/her leaving the home for home or recreation. These people could be in their own home, institution or other place of care.

dignitaries such as politicians), detailed minutes, and comprehensive notes from workshops conducted throughout the conference were again widely distributed. This approach was used until 1988.

### **Three: Formalisation and Control Stage**

An organisation at this stage is likened to having reached adulthood, developing a more formalised structure with the emphasis moving towards achieving efficiency. With this shift to efficiency, the control of decisions and the operations of the organisation become centralised. Specialist areas are formed to meet the range of tasks and activities now required within the organisation by creating departments (Bartol, Martin, Tein, & Matthews, 1998). In the DPA working parties and sub-committees were established with more of the responsibility for the management of tasks and projects moved onto the Secretariat. Moves were made to formalise systems within the regional assemblies. The focus of organisations during this time is to consolidate their position, achieving better direction and continued growth.

In her interview Marilyn Baikie discussed how she continued with a project that was started by John Stott, facilitating the development of the organisation's first Policy Manual. She saw this as being significant as

*... it actually gave us something to base our submissions on. Up until then it had just been a gut feeling... that this is probably how DPA feels... Having the Policy Manual gave us something we could quote from that this is DPA policy... It also gave the regions something as a basis for their work...*

A significant policy area focused on at that time was Human Rights. This provided the platform from which a ten-year campaign was based that began during the entrepreneurial stage and reached a conclusion at the beginning of the formalisation and control stage. The campaign's focus was to have disability included in Human Rights legislation.

### **Human Rights**

The DPA has had a strong emphasis on human rights issues from the beginning. In 1988 Quentin Angus, then convenor of the legislation portfolio, recommended that the DPA work to ensure that the Human Rights Commission Act 1977 be amended to

include disabled people (DPA Conference Reports, 1988). There was a strong belief within the disability movement that until disabled people were recognised and afforded the same rights to protection from discrimination as other citizens that it would be almost impossible to change their marginalised position in society. An article by Dave Henderson outlined the key issues:

At the outset... all of the discussion, all the unfulfilled recommendations of different reports, and all the unfulfilled hope of people with disabilities, take place against a backdrop of daily discrimination in areas as diverse as employment, housing, the opening of bank accounts, taking out of home mortgages, participating in superannuation schemes, travel, and participation in public entertainment such as an evening at the theatre (1992:6).

The DPA made numerous submissions to Government, including the Royal Commission on Social Policy, to have the Act amended. It appeared that the goal was to be achieved when the Labour Government introduced a Human Rights Commission Amendment Bill, however, as Dave explained, the Labour Government went out of office before the Bill was passed. He argued that the need for an amendment became more pressing when the National Government repealed the Employment Equity Act 1990, referring to a report from the Equity in Employment working party, which recommended that:

To ensure the full integration of people with disabilities into the normal life of the community the Human Rights Commission Act 1977 be amended so that it specifically prohibits discrimination on the grounds of physical or mental disability or health status (Henderson, 1992:6).

Henderson reflected that in spite of various ministerial undertakings that the Act would be amended, the DPA was again disappointed when informed that fast-track amendments that were to proceed in 1991 would only cover age discrimination. The DPA continued to lobby both regionally and at the national level and to make submissions. It was argued that the omission of disability coverage under the Act went against principles contained in many United Nations declarations and covenants which New Zealand governments have ratified, as well as many recommendations from government working parties. The DPA was also concerned that disability was not included under the proposed Bill of Rights 1989, noting that the working party for that Bill recommended the inclusion of disability.

The limited grounds of non-discrimination protected by the Human Rights Commission Act is contrary to overseas trends...

The long neglected rights of the disabled are now being asserted and championed nationally and internationally as more emphasis has been placed on creating international norms of non-discrimination against people with disabilities (Henderson, 1992:7).

In her interview Anne Hawker discussed the strategies used in the final stages of the campaign. The DPA formed alliances with other marginalised groups such as people who were HIV positive and gay groups who were also campaigning for their inclusion under the Act. Anne stressed the importance of this, which she believed demonstrated that the disability community was not prepared to promote their needs in isolation, even if the stance put at risk their chances for success.

The Human Rights Act was finally amended to cover disability, sexual orientation, medical status and age in December 1993 and came into effect 1 February 1994. The focus for the DPA then moved to promoting education and awareness programmes within the disability community about their rights, and supporting people to make complaints when discrimination occurred. Government was also lobbied to ensure appropriate levels of resources and education programmes were made available to the Human Rights Commission.

DPA now challenges the Government to commit sufficient resources to make the Act really work. The tasks of public education and handling sometimes complex complaints will take considerable resources. While we recognize that the Commission already has been given some increased staffing and resource, it would be very easy for the Commission to become overstretched (Hawker, 1994:3).

Anne argued that education and awareness programmes about the changes in the Act were required at all levels of the community in order to address the discrimination experienced in areas such as employment and housing. She summed up the significance of this legislation for the disability community.

This Act, then, is about a shift in attitudes and in actions in the whole community, not just about one group or a number of groups celebrating victory on 1 February. New Zealand has a huge task ahead of it, and political will and resources must not be the reason for failure (Hawker, 1994:3).

## **The Changing Face of the DPA**

The period between 1993 and 1996 saw significant organisational changes occurring as the DPA explored ways it could continue to operate in the changing political and economic environment. In 1993 the DPA celebrated its 10<sup>th</sup> anniversary, buoyed by its successes and aware of the rollercoaster ride it had gone through as it progressed through the organisational developmental stages. The theme for the conference that year was “Into the Second Decade – Meeting the Challenges” and was seen to signal the end of the tumultuous first ten years of the DPA and the beginning of a decade of consolidation as well as growth. A report from the 1993 AGM and conference stated how

the overall feeling was that DPA had finally ‘come of age’. This maturity was symbolised by [the] acceptance of a comprehensive development plan and by the election of Anne Hawker as president (by a large majority) on a platform of DPA recognising the need to change while building on the basis of what has been achieved so far (Smith, 1993:3).

It was clear that the DPA was facing some significant challenges. Smith reports Don McKenzie as highlighting some of these in his address.

Amongst these challenges DPA’s needs for adequate financial and human resources, working at understanding each other’s special needs, taking a proactive role in support services changes as recognised equal partners, and breaking the charity mould as the prime source of support for people with disabilities (Smith, 1993:5).

The reference to the need for changes in support services and the breaking of the charity mould was in response to challenges from within the DPA about the appropriateness of continuing to have non-disabled people as full members. A remit was put forward to that AGM for voting rights to be restricted to “individuals who self identify as having a disability” (Smith, 1993:5). The remit was lost but created some heated discussion. John Stott argued it was essential to maintain the status quo in order to preserve the original partnership upon which the DPA was based. He urged the DPA to prioritize its objectives, providing a national perspective.

Only when we can show such maturity across the broader front, will we really develop into the organisation originally envisaged as DPA (Stott in Smith, 1993:5).

At this same meeting it was decided to change the DPA's name to the Assembly of People with Disabilities. It was argued that this change was in keeping with the organisation's original identity and values while "updating our terminology and image" (Smith, 1993:5). However, in Chapter two it was argued that the term "people with disabilities" suggests that 'disability' is an appendage only and denies the identity and experiences of disabled people. It should be noted that this change went against the fundamental philosophies of Disabled Peoples' International to which the DPA is affiliated. The name change has not been formalised in the Constitution but is used on stationery and in official publications.

In her interview Anne Hawker was clear that when she took on the role of National President she wanted to streamline administrative and organisational structures and to raise the organisation's profile. There were a number of areas she focused on. Job descriptions for each of the positions within the National Executive Committee and terms of reference were developed so people knew what they were expected to do. The system of having portfolios and sub-committees that had evolved was reviewed with many being disbanded and replaced with a smaller number of working groups that focused on specific projects.

Anne believed the project in 1995 to update and re-publish the Policy Manual developed during Marilyn Baikie's term was a crucial step taken in the DPA's development (DPA Annual Report, 1 July 1995 – 30 June 1996). In her President's Report she stated that:

Policy gives DPA national consistency and a framework from which to address issues affecting the lives of New Zealanders with disabilities. Discussed and ratified by all regional assemblies, our policy is the binding voice of DPA (Hawker, 1996:2).

Anne emphasised that the production of a new Policy Manual alone does not bring policy alive. She warned that everyone in the DPA needed to understand why policy is so important, explaining that the focus for that year had been to ensure members of the National Executive Committee and Regional Assemblies were educated about the role of policy in the organisation. Working from this base, Anne argued it was important for the DPA to then develop strategic plans that outline how the organisation would work in pursuit of its vision, ensuring that the policies were brought to life. Anne concluded that through this process the National Executive Committee learned to be realistic about

what could and what could not be achieved, something she felt the disability community in the past had found difficult to accept. She warned

... we do need to think and work strategically – recognising that the whole world can't be changed overnight – if we are to be effective and avoid burnout (Hawker, 1996:2).

At this stage of the organisation's development the approach of leaders generally moves from being entrepreneurial to being professional managers (Bartol, Martin, Tein, & Matthews, 1998). Many organisations experience an increase in hierarchical information processing, making it slow to respond to the needs of the membership, and as was the case for the DPA, slow to respond to the demands created by social, economic and political developments. This may bring about a crisis within the organisation when members feel there are detrimental effects as a result of these new organisational processes and centralised controls (Bartol, Martin, Tein, & Matthews, 1998).

In her interview Anne discussed how she brought in changes to the format of the DPA conferences so that they had more vigorous debates around a particular topic rather than having the conferences covering a wide range of topics in a short space of time. She argued that this helped the DPA to be more focused on what it wanted to achieve, and to follow the identified priority projects through. Processes for raising topics at AGMs became more regulated.

Another change to the AGM format I observed was the running of a session called 'Open Forum' where people could raise any issues they wished. This session was only allocated an hour and did not appear to offer the same opportunity for an open exploration and discussion of the topics/issues raised as is possible in a workshop setting, with many issues simply being noted.

During this stage there was a strong emphasis on clarifying the role of the DPA, and particularly the regional assemblies. Training manuals were developed for regional assemblies that outlined possible strategies for fundraising and organising political action at the local level through to discussing ways in which they might work with their local city councils. These manuals were intended to ensure that the regional assemblies were aware of their roles and responsibilities, and what they were allowed and not allowed to do, as well as being a resource for regional development. Anne recalled a

'memorandum of understanding' developed between the DPA and Disability Information Centres throughout New Zealand. It was intended to clarify the differences in the roles of the two organisations as the National Executive Committee was concerned that the regional assemblies were getting bogged down trying to provide a range of services that were not within their brief.

It was during this time that the DPA faced a major challenge from one of its member groups. The Association of Blind Citizens withdrew from the DPA, as they did not agree with the approach taken by the DPA to present a unified agreement on issues. They did not accept the DPA as **the** speaking voice of the disabled on all issues. The differences came to a head when the DPA promoted the concept of mainstreaming as the basis for its education policy, rejecting the notion of retaining some special schools. The Association of Blind Citizens disagreed strongly, arguing that the option for special schools should remain. Incidents such as this coupled with the fall in membership (discussed in Chapter 5) and reports from some regional assemblies that they were having difficulties getting people involved at the grassroots (DPA Annual Report, 1 July 1997 – 30 June 1998:) indicate that the DPA was in a state of crisis. It had to work through some significant challenges if it was to continue to successfully function and grow.

#### ***Four: Elaboration-of-Structure Stage***

At this stage the focus for the organisation is on revitalisation, with an emphasis on innovation. The leadership at this stage extends its focus on creating opportunities at the various levels of the organisation to promote this innovation. Hierarchical organisational and communication processes that were established in its formalising phase are often reviewed and may be streamlined, with many functions being decentralised. There is a renewed emphasis on developing and implementing strategic directions. A common focus at this stage is on cost cutting and achieving new efficiencies as the organisation repositions itself to ensure not only its survival but also its ongoing growth (Bartol, Martin, Tein, & Matthews, 1998).

Paul Gibson made it clear that the beginning of his term as National President that he wanted to ensure the DPA as an organisation was revitalised. His focus was to review the values and philosophical base of the organisation, as well as to address the financial

and administrative needs of the DPA as an organisation. In his address at the AGM in 1998 he stated:

Another challenge is the redefining and articulating of our values, and shaping our organisation so it becomes the expression of those values. A current initiative is the process of constitutional update. Let us not get stuck on the semantics but ensure that we have captured the heart, soul and vision of the organisation – it is people.

DPA is our organisation. DPA is not about sitting on committees. It is about our values and vision. We need to make it work for ourselves. Your participation, and the participation of others like yourselves, is essential. We must sharpen our understanding of our values and vision, promote these to the wider community, and relate these to issues as they arise... (Gibson, 1998:2).

Paul (1998) stressed that everyone had a role to play in achieving the organisation's mission, stating that the organisation needed to attract more people in order to share the workload. In his interview he discussed how he wanted to ensure the membership at all levels of the organisation (including the National Executive Committee) were representative of the disability community, expressing his concerns that the membership seemed to be comprised predominantly of people with physical impairments. Paul felt this resulted in the organisation focusing more on issues related to disability support services at the expense of other issues such as employment and education. To this end, Paul outlined strategies to be introduced including a marketing plan to assist regional assemblies to increase their membership. He also made a commitment to ensuring there would be opportunities to develop the skills of young disabled people "so they can build on past gains and take on the challenges of the future" (DPA Annual Report, 1 July 1997 – 30 June 1998). It was his hope that a youth leadership programme would be developed and implemented within the organisation by 2000.

A year later Paul discussed challenges facing the DPA (DPA Annual Report, 1 July 1998 – 30 June 1999), referring to them as 'spurs for rejuvenation'. One such challenge came from the national Maori disability hui for the DPA to improve its performance within the policy area of the Treaty partnership and in developing its grassroots, its membership base.

Issues for Maori people in the DPA have been longstanding. Calls for the DPA to recognise its responsibility to develop a partnership with Maori under the Treaty of

Waitangi was first formally raised at the DPA AGM and conference held in Hastings in May 1992. At that meeting an amendment was made to the Constitution to provide for the appointment of a National Maori Adviser (see Chapter 4). John Moananui was appointed as the interim National Maori Adviser, and Charles Mohi, who was DPA's Kaumatua, supported him in this role. An informal paper written by the DPA's Chief Executive Officer, Gary Williams<sup>18</sup>, in 1999 suggested there were initial difficulties as there was no infrastructure to support the position, something the NEC recognised halfway through 1995. John had continued to work beyond his expected finish date, as there was no process to select another National Maori Adviser. Therefore in 1996, a working group was established to develop the infrastructure required, including a job description for the position. These were presented to the NEC for final approval in early 1997. That year Tamehana Tai-Rakena was appointed to the position for a two-year term.

The Constitution does not specify the selection process to be used for this position. To date the National Executive Committee has handed the selection process to the Maori members of the DPA. It was intended that this selection process coincide with the AGM every two years<sup>19</sup>. However, the participants of a Hui in Whangarei superseded this process in 1999, when they endorsed Tamehana for another term, a decision that was later ratified at the 1999 AGM.

Despite the introduction of the National Maori Adviser position and the subsequent development of an infrastructure to support the position, there were still concerns at the lack of overall progress in bringing Maori disabled people together to address their issues. The need for increased consultation and links among the National Executive Committee, the regional assemblies, and Maori was highlighted (DPA Annual Report, 1 July 1998 – 30 June 1999). Earlier reports stated the DPA had encountered difficulties accessing sufficient funds to enable national hui to be organised on a regular basis, and this was a constant source of frustration (DPA Annual Report, 1 July 1996 – 30 June 1997). In 1998 additional funding for travel and accommodation for the Maori Adviser was made available by the National Executive Committee to enable consultation on Maori and partnership issues (DPA Annual Report, 1 July 1998 – 30 June 1999).

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<sup>18</sup> Gary Williams succeeded Dave Henderson as Chief Executive Officer in 1999.

<sup>19</sup> At the AGM in 1997 it was decided to hold the DPA conference every second year, with the AGM still occurring annually (Annual Report, 1 July 1997 – 30 June 1998).

Paul Gibson's concern about the need for the DPA to encourage greater input from younger disabled people and the challenge from Maori disabled people that the DPA develop structures and processes to encourage greater Maori participation highlight the organisation's difficulties in being truly representative of the disability community. In the initial stages the organisation's leaders focused on ensuring that people with a range of impairments were able to participate. The emphasis was therefore on looking at accommodations that needed to be made, such as having publications and other DPA material available in a range of formats for Blind and visually impaired people to access and later, the provision of interpreters at meetings for Deaf people. However, the organisation was challenged at the AGM in 1986 to "take specific cognisance of the needs of disabled women" (DPA Conference Proceedings, 1986:28) in determining its goals for that year, with the decision being made at that meeting to establish a Women's Affairs portfolio. This signals a beginning of the recognition within the DPA membership that disability issues cannot be seen solely in terms of impairment-related needs, but rather are impacted on by wider issues of gender, sexual orientation, race and class. These challenges are ongoing for the organisation as it explores ways to meet the needs of its diverse membership.

Another challenge facing the DPA in 1999 is the difficulty in accessing adequate funding on an ongoing basis to sustain the level of activity expected by the membership. At the AGM in 1999 Paul outlined the extent of the financial crisis facing the DPA.

This financial year we lived well beyond our means and this is not sustainable. While the expectations that we as people with disabilities have of our organisation rightly continue to grow, we can't do everything. Plans are well under way to diversify our funding base... (Gibson, 1999:3).

Paul was clearly looking to involve the wider membership in working through these difficulties.

We also must facilitate more volunteer involvement. How can you as a member, corporate or individual, help? (Gibson, 1999:3)

He believed it was important for the organisation to work together in facing these challenges in order to set a solid foundation from which to continue working in the future.

The expectations that we as people with disabilities have of our organisation again will have risen. But because of the contribution you make now, it will be a stronger organisation. Looking beyond 2000, some of our current challenges will be behind us, and there will always be new challenges (Gibson, 1999:3).

This fourth stage represents a crucial turning point for the DPA, with the organisation facing issues such as a reduction in its membership, insecure funding, and an apparent stagnation in its activities as it focuses on streamlining its organisational structures. The challenge for the current leadership is to consider how the organisation can continue to encourage innovation and continue to be the focal point for the disability movement in New Zealand whilst trying to maintain stable organisational structures, including a stable funding base.

## **Conclusion**

In this chapter I have briefly examined the development of the disability movement as a social movement. Like other social movements the disability movement is not just reacting to the marginalisation of disabled people; they are actively involved in consciousness-raising within their membership and in the wider society. The disability movement explores and promotes different cultural values and norms in relation to disability than are evident in current dominant discourses. As a result, they began to challenge their marginalised position in society, with demands being made for physical, structural and attitudinal barriers to be addressed in order for disabled people to be recognised as citizens with rights.

The DPA provides the organisational structure for the disability movement in New Zealand. From the beginning the DPA has been seen as a unique and innovative organisation working to promote the needs and issues relating to disability in order to bring about change. As well as working at this social and political level, the DPA has had to develop nationwide structures and systems from a central point in order to be able to incorporate both the work and the needs of its diverse membership. This has presented unique challenges to its leaders. In this chapter I have identified the stages the organisation moved through as it became better organised, formalising its structures in order to manage and coordinate its activities. This has sometimes created tensions within the organisation, as its leaders have had to balance the pursuit of social and political change with the need to develop organisational systems and structures.

I have outlined how the DPA was instrumental in pioneering two revolutionary services, Total Mobility and Teletext, which were initially administered by the DPA but are now integrated into mainstream public services. These two projects were significant as they both resulted in the facilitation of improved opportunities to be informed of and to access services and facilities for disabled people, enabling their participation in the community. Another successful campaign conducted by the DPA was for the inclusion of disability under the Human Rights Act, which was finally achieved in 1993, and acknowledged that disabled people are citizens with the right to be protected from discrimination. This inclusion of disability in the legislation has provided a platform from which people can demand the provision of services and the removal of barriers, both structural and attitudinal, as of right and not as a favour.

The challenge for the organisation and its leaders in 1999 and beyond is to ensure innovation is encouraged in the planning processes in order to achieve DPA goals, and to encourage its continued growth and development. The data presented in this chapter and informal discussions I have had with people within the DPA lead me to conclude that during the second decade of the DPA's operation the focus has been on maintaining itself, with particular emphasis on policy development at the National Executive level. This has resulted in a growing level of frustration expressed by many in the regional assemblies that the organisational direction is imposed from the 'top down', with minimal opportunities for consultation and input from the regions. This may account for the fall in membership and the related difficulties many regional assemblies' report in attracting people to become involved in local activities. In focusing more on infrastructure in order for the organisation to survive it appears the DPA has become isolated from the wider disability movement.

In the following chapter I review the key themes of this thesis. I then discuss some of the main issues facing disabled people in New Zealand as identified by the participants in my research and examine what the future role and possible future directions might be for the DPA.

## Chapter 8

### ***Future Directions for the DPA and the Disability Movement in New Zealand***

#### **The DPA and the Disability Movement**

This chapter reviews the key themes of my thesis, including a review of the stages of development of the DPA as it worked to survive and grow as an organisation and maintain its role in the disability movement. Some international influences for the disability movement in New Zealand are examined, and a brief comparison is made of aspects of the development of the British Council of Disabled People with that of the DPA. Another key theme reviewed in this chapter is the power of language and disability, with discussion on the need for the DPA and the disability movement to be clear on how disability is defined. Finally, some of the main issues facing disabled people as identified by the participants in my research are discussed, with possible directions for the DPA being explored.

In my research I asked the participants if they felt there was a future role for the DPA, and if so, what they saw that role to be (see Interview Schedule, Appendix 1). All responded that they felt there definitely would be a future for the DPA. In his interview Paul Gibson explained why he felt the DPA would still have a role in advocacy and lobbying at the national and regional levels, and in facilitating ongoing networking opportunities for disabled people.

*People with disabilities are still marginalised in society. They are underrepresented in employment, educational achievement etcetera, and that will be so for a while whatever we do now. You can only chip away at these things at a slow rate... I think the role; there is a role in society for equity groups, as I call them... The more a government wants to improve the position of those potentially more disadvantaged people in society... the greater the role for DPA will be... Also, not just at the government level, but local government level, influencing organisations, influencing employers, educational institutions... and although the primary outputs... are not for providing support services for people with disabilities, most people, all people do not function at their best in isolation... There is a role for an organisation to facilitate networking...*

Paul recognised that although some changes had occurred to improve the situation for disabled people, they are a marginalised group in society and therefore groups such as the DPA were needed to work at various levels in society to achieve further change.

It is important to examine key issues the wider disability movement needs to address in order to begin identifying a future role for the DPA. As part of this discussion it is useful to draw on some of the experiences of the British disability movement, and in particular, the British Council of Disabled People, and make some comparisons with the New Zealand situation.

### ***International Influences***

In their book *Disability Politics: Understanding our Past, Changing our Future* Oliver and Campbell present an outline on “the process of self-organisation of disabled people that has occurred over the last thirty years in Britain” (1996:17). Oliver and Zarb note:

That while nowhere in the world have social movements been successful in overturning the status quo, they have been able to place new issues onto political agendas, in presenting of issues in new forms and... in opening up new areas and arenas of political discourse (Oliver & Zarb, 1997:213).

Campbell and Oliver’s book outlined the development of the British Council of Disabled People (BCODP) as the organisational focus for the British disability movement. They highlighted some of the debates that occurred and conflicts that surfaced as disabled people challenged the dominant discourses of disability and their marginalised position in society. It can be argued that many of their observations are relevant for the disability movement in New Zealand, and, in particular, the DPA.

### ***Who Should be Members?***

The BCODP (originally called the British Council of Organisations of Disabled People) was formed in 1981, and like the DPA, traces its beginnings to IYDP activities. However, unlike the DPA, the BCODP initially was comprised only of “democratic organisations that were accountable to disabled people” (Campbell & Oliver, 1996:47), which they argued was an important feature for any organisation identifying as being part of the disability movement. The BCODP did not allow individuals to become members until 1995 (when the organisation changed its name to the British Council of

Disabled People), as they believed that the organisation could easily have been hijacked by individual agendas and lose the focus on the wider political issues. Service provider organisations and non-disabled people were not able to join the BCODP, as Campbell explains.

Simply by breaking away from those who work on our behalf and finding a space where we could beg the question, why are we excluded from society? And how can we break in? This was the key to unlocking some of the fundamental principles of the Social Model of Disability that we hold so precious now. Those years of debate were vital for the development of our collective consciousness...(Campbell 1997:82).

This has remained a key principle for the BCODP. Campbell and Oliver note that:

The main problem was that disabled people in their isolation were ignorant about disability issues (Campbell & Oliver, 1996:68).

From the beginning they argued that as disabled people are a marginalised group they needed their own space to share their experiences and formulate a collective analysis of disability (see Chapter 2). They argued this ensured that those who not only worked on their behalf (such as service providers and medical professionals) but also formed and promoted dominant discourses would not influence disabled people as they worked through a consciousness-raising process.

This is a key difference between the DPA and the BCODP. My discussion in Chapter five highlights how for many in the DPA it is a point of pride that the membership is diverse and that they are able to work in partnership with service providers and non-disabled people. In her interview with me, Marilyn Baikie recalled some of the reactions she got when explaining how the DPA worked.

*It was always good to try and explain how DPA worked because it was always quite unique in the world... Having the RI and DPI sectors working in together... We often got the comment that it couldn't possibly happen...*

Mary Stott explains in her interview how she believes

*[DPA] needs to advocate for disabled people in New Zealand and it's better to be one body than a whole lot of different bodies, trying their own little actions on their own, if you've got one combined body it is easier... While you've got the body you've*

*actually got people talking together, if you've got them all in separate factions... there's a lot of aspects where they can join together and discuss them even if they don't totally agree at least you get some dialogue.*

Marilyn agrees, stating that she believes it also makes good sense in relation to the use of funding and other resources.

*It all seems such a waste of resources, having the two organisations. When they were funded separately and it was so easy for governments to play them off against each other which they tended to do because the R. I. organisations generally had more money and so they got the say when it came to lobbying to government... I think we were seen as a world leader because we could get the two organisations working together.*

This conflict for funding is an issue the BCODP also had to address. They discussed how the organisation had constant difficulties accessing 'disability' funds and to be recognised as a viable organisation to be consulted as they competed against organisations such as RADAR<sup>20</sup> and charity-based service provider organisations. They noted that:

It's because of the entrenched, established groups... People keep saying 'You've got RADAR, you've got this, you've got that, what do you need BCODP for?' (Campbell & Oliver, 1996:79).

As with the DPA, there was considerable debate within the BCODP as to whether organisations such as RADAR should be included, with one contributor noting the concerns from some if they were excluded.

Well you can't exclude the RADAR's of this world, that's where all the power is and you can't expect to get anywhere without having a system for including them (Bradshaw, cited in Campbell & Oliver, 1996:78).

However, they suggest that non-disabled people can play an important role in supporting disabled people.

In a mass movement among disabled people, for disabled people... the role of able-bodied people, experts, professionals and anyone else, would be to support disabled

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<sup>20</sup>RADAR is the Royal Association of Disability and Rehabilitation, and is the equivalent of Rehabilitation International New Zealand.

people to articulate and to take the lead in their own emancipation (Campbell & Oliver, 1996:63).

The BCODP experienced considerably greater difficulties in accessing government funding and lobbying processes than organisations such as RADAR. The BCODP has often been criticised for being so rigid. However, they argue the organisation and the wider British disability movement is stronger because they have had these crucial debates.

### ***Clear Analysis***

Not only was there a great deal of conflict in deciding who would be in BCODP, there was considerable debate over fundamental aims and objectives (Abberley, 1997:85).

The BCODP used the document *Fundamental Principles of Disability* published by UPIAS<sup>21</sup> in 1976 as the basis for its statement of aims and objectives. Campbell and Oliver explain how reframing their understanding of disability was crucial for the disability movement to be clear on the issues when working for structural and attitudinal changes in society.

The Union, at that time, was very committed to the political requirement facing disabled people, which was to produce a rigorous, dependable explanation of disability in social terms that enabled society itself to be seen as the focal point of disabled people's attention... Loose networks of liberal-minded, well-meaning disabled people were not actually going to produce the cutting edge that was necessary to start a mass movement (Campbell & Oliver, 1996:66).

The UPIAS principles were later expanded by Oliver (1990) and became known as the Social Oppression Theory (see Chapter 2) or the social model of disability. This model provided a clear analysis of disability and enabled disabled people to challenge injustices as Sullivan explains.

The beauty of the social model is that in separating disability from impairment and relocating it in social structures, disabled people were provided with an agenda for the elimination of disability. None or few of us can change the reality of our impairments – we're stuck with them – but we can militate to change the disabling society, to eliminate the social structures which disable us, which exclude us from

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<sup>21</sup>UPIAS is the Union of the Physically Impaired against Segregation and was formed in 1972.

education, which exclude us from satisfying and well rewarded employment, which exclude us from the lifestyle expectations and standards of living enjoyed by our non-impaired counterparts (Sullivan, 1999:3).

Campbell and Oliver argue that the adoption of the social model by the BCODP and the wider disability movement in Britain has provided a set of principles that people can identify with, and a solid base from which to set a political agenda.

... I think the thing that started to make it clearer was the total acceptance of the social model as being the core of the movement... It was something people could adopt and feel part of and most importantly use as a tool (Wood cited in Campbell & Oliver, 1996: 89).

It can be argued that there has been a lack of ongoing debate within the disability movement in New Zealand, and particularly within the DPA, around definitions and analyses of disability, and what the fundamental principles are that should inform political and social action. This lack of debate might explain the loss of direction felt by many within the DPA currently and it can be argued that it is reflected in the drop in membership and the apparent apathy experienced by many regional assemblies (see Chapters 5 and 7). Sullivan expresses similar concerns about the apparent lack of challenge and intellectual activity within the movement, criticising its approach as “being too polite, timid and generally apathetic, seeking approval and acceptance rather than radical change” (Sullivan, 1999:10).

... I think the disability movement has stopped doing the intellectual work it needs to do if it is to be a vibrant, challenging movement for social change. Does it, for instance, have a vision of what a nondisabling society might look like and how it might operate? Has it started thinking about the implications a nondisabling society might have for all of its citizens? Or does it just want disabled people to be able to join the game as it is? (Sullivan, 1999:10)

In his interview Paul Gibson outlined his commitment to work from the social model when coordinating DPA activities.

*We need to push that most of the barriers to achievements of people with disabilities, or their participation [in their communities] are out there. We need to make that understood by decision-makers, government, employers, wherever they may be. And by people with disabilities themselves...*

However Paul believes there is very little understanding of the social model by disabled people in New Zealand. He argues that the people who have this knowledge and understanding of the model have attended tertiary education and are therefore an elite group. This, Paul believes, creates a barrier in encouraging the DPA and the wider disability community to work from the social model.

*I do see a gap, even from the disability community, it's hard to bridge that. While I'd say there's almost an elite of people with disabilities that are completely in tune and understand that philosophy... who have the opportunities to get tertiary education, to mix with the right crowds almost and make that distinction between a medical model and a social model. I think people with disabilities who belong [to DPA] still instinctively know what is right and still have some instinctive grasp of the issues. And the model... But we still try to challenge DPA to try and lessen that gap. So that that instinctive grasp can be articulated by that group and so that in the wider community it's understood as well.*

Sullivan agrees that there appears to be a poor level of understanding of differences between the medical model and the social model within the DPA, and argues that this confusion that has resulted in a lack of clarity about exactly what it is the DPA is advocating.

Why does the focus always seem to be on various kinds of 'disabilities' rather than institutionalised disableism? Why this equivocation? I think one of the answers lies in language and in terminology compounded by a lack of conceptual clarity and understanding of the exact nature of the two models (Sullivan, 1999:3).

As a result of this lack of conceptual clarity Sullivan suggests the DPA is

... trapped by their terminology and we get statements that don't say what they mean; statements which are conceptually messy, inconsistent and contradictory (Sullivan, 1999:6).

Finally, Sullivan warns that this lack of intellectual debate within the disability community and the subsequent confusion surrounding the social model in New Zealand will greatly impact on the development of future disability activists.

... This general absence of intellectual activity means that young people coming through do not have the historical background to the debates and struggles nor do

they have a clearly articulated structural analysis which encourages militancy...(Sullivan, 1999:10).

If the DPA and the wider disability community do not address this it will be increasingly difficult for them to attract new people into the movement, jeopardising the organisation's survival in the future. In their interview Lindsay and Mary Buick-Constable observed that:

*For DPA to continue in the future, it needs to attract new blood and to encourage a greater level of political activity.*

Paul Gibson argues that these needs can be addressed and that the DPA has an important role to play in developing programmes to ensure the empowerment of disabled people now and in the future by facilitating leadership opportunities at the national and regional levels.

*We need to be an organisation which can reflect the needs and wishes of our diverse membership, be deliberate in building the capacity for leadership, not just within DPA but so there are people with disabilities who are leaders in employment, in disability organisations as providers, so they're out there in the community everywhere. There's a role for DPA to build that.*

### **Development of Regional Assemblies**

Considerable importance is placed on regional assemblies in the structure of the DPA. Each of the National Presidents and their administrations have viewed these regional assemblies as being the grassroots of the organisation, alerting the National Executive Committee to issues, providing material that can be used in submissions to government bodies and providing feedback on the impact of government policies.

It can be argued that there is potentially a greater role for regional assemblies in encouraging and promoting opportunities for disabled people to work together and undertake political action in their local communities and regions. Foucault argues that as power relations are exercised at the level of daily life resistance must be played out at the local level (Foucault, 1980). Such an approach would enable disabled people to meet and share their stories and experiences of disadvantage and discrimination that are inherent in the dominant non-disabled structures we live and work within.

Disabled people can be empowered to resist their marginalised position by working through a process that Paulo Friere identifies as conscientization. Munford and Sullivan (1997) outline this process whereby individuals and groups move through three stages of consciousness – magical consciousness, naive consciousness and critical consciousness. Briefly, Friere identifies that people at the level of magical consciousness are preoccupied with survival and are unable to locate their problems in wider social/historical context, and passively accept their position of oppression. Individuals at the level of naive consciousness focus on ‘fitting into’ society and the emphasis tends to be more on working for individual rather than structural changes.

The findings of this research suggest that the DPA is currently operating at the naive consciousness level as their policies focus on seeking reforms of existing structures. This is evidenced in goal statements of the DPA. These focus on the organisation being a speaking voice of people with disabilities, providing information and advice, empowering people with disabilities to have equality and full participation in society, monitoring services and legislation, and being part of an active and credible international disability community. Whilst the DPA goals acknowledge structural barriers that disadvantage disabled people they do not address the need to create a non-disabling society.

At the critical consciousness level people are no longer prepared to work for reform within structures, rather the goal is to transform systems so that people are able to become more fully human, with the emphasis moving to self-reflection and group action. This approach underlies the analysis and social and political actions of the British Council of Disabled People.

Munford and Sullivan argue that to identify as an oppressed group is not to take on the victim role, instead:

Individuals see themselves as integrated subjects rather than adapted objects... Differences between and within disabled people are acknowledged and valued. This may lead to some people adopting the disability activist position, and therefore to name disability as ‘social oppression’ is not the defeated cry of victims, but the call of social change agents (Munford & Sullivan, 1997:27).

They conclude that in order to resist and transform these structures community based actions based on strategic coalitions are needed (Munford & Sullivan, 1997). By

encouraging and promoting opportunities for activity within the regional assemblies the DPA would be able to increase its membership while enabling disabled people to work through this process of conscientization, developing a critical analysis of disability. Supporting disabled people to take action at their local level enables coalitions with other oppressed groups to form and develop, forming a broader global perspective which allows people to recognize common themes in their experiences. Success in working on issues at the local level also inspires confidence in people to feel they are able to continue building networks and work cooperatively to address issues at the national and international levels.

### ***Changing the DPA Constitution***

An organisation's Constitution outlines the rules and regulations its membership is required to comply with to ensure the organisation operates in a legal and democratic fashion, in line with legislative requirements. A Constitution also incorporates statements of the fundamental principles, aims and objectives of the organisation, which clearly outline its purpose.

The DPA's Constitution has remained largely the same since it was first written in 1983. In his interview Paul Gibson felt the DPA has evolved beyond the principles contained in the Constitution. He describes the DPA as a consumer-driven organisation, and believes the Constitution does not clearly accommodate this<sup>22</sup>.

In 1999 the National Executive Committee initiated a process for reviewing the Constitution. Paul was conscious of the risk that the membership could become 'bogged down' with pedantics and legalities rather than debating the broader principles that govern the DPA (see Chapter 5). A *Review of the Constitution* questionnaire (1999) was therefore distributed to the membership to stimulate discussion. Questions addressed areas such as whether the organisation's name and logo should be changed, the need to reformulate the organisation's aims and objectives, whether the composition of the organisation's membership needs to change, and whether the composition of the National Executive Committee and Regional Executive Committees needs to change. Sullivan expressed some amazement that the organisation is focusing on questions such

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<sup>22</sup>This statement refers to the inherent conflict with the requirement to have as a majority corporate member representatives and disabled people on both the National Executive Committee and the Regional Executive Committees.

as its name and the format of its Constitution at a time when action needs to be taken on political issues that directly impact on the lives of disabled people.

Look at our national organisation that is supposed to give leadership. DPA started off as Disabled Person's Assembly; it now calls itself the National Assembly of People with Disabilities. Now they're looking for another name change (which is probably a good thing)! There are two problems with this. First, members can get caught up in this and avoid the real issues. Second, this is being done at a time when support services are being cut to impaired people across the country. They sure have their priorities sorted out (Sullivan, 1999:5).

However, Paul sees that the review of the Constitution

*... will be an opportunity for a debate at the grassroots level again of what defines DPA. Where we want to go... But that's going to be an interesting exercise too, for the membership to define what it is and to write that down in a Constitution and to agree on it... And it does require a vision of DPA. And almost a clarification or some idea or some definition of what is impairment, what is disability.*

In Chapter seven I discussed organisational stages of development the DPA has worked through, and argued that it is currently at the elaboration-of-structure stage. At this stage leaders work to revitalise their organisation, creating opportunities to promote innovation, and look at ways in which to streamline its structures and become more efficient. There is a renewed emphasis on developing and implementing strategic directions at this stage (Bartol, Martin, Tein, & Matthews 1998). It can therefore be argued that it is appropriate for the DPA to review its organisational structures and the philosophy from which the organisation operates. The process of the Constitutional review may be a useful catalyst to bring people together to work through the process. However, in order for the process to be successful the membership need to be actively involved throughout. The *Review of the Constitution* questionnaire (1999) outlined how the membership would be consulted up to three times and that any changes to the Constitution would require 75% support of all votes cast at an Annual General Meeting. While this process might be expedient, efficient and comply with the rules within the current Constitution, it does not appear to offer opportunities for comprehensive discussion and debate on the structure of the organisation or the values that define its objectives and subsequent purpose.

It is important that the DPA membership and the wider disability community openly and vigorously debate issues around language and disability and the experiences of disabled people, and to develop a model to work from that provides strategic directions for the disability movement to work for structural change. Once this process has begun the challenge will be for the disability community, including the DPA, to clearly articulate their analysis of disability and vision of the ideal society.

### ***Involvement in the International Arena***

In Chapters four and five I discussed how the designers of the DPA intended that the organisation should represent disabled people in New Zealand both nationally and internationally. Leaders from the Disabled Peoples' International attended the inaugural AGM (see Chapter 5) and Marilyn Baikie held the position of Vice-President of the Asian and Pacific region of the DPI (see Chapter 6). The DPA has also been actively involved in the Rehabilitation International from the beginning, and their input has been highly valued. For example, a requirement of the position of the Chief Executive Officer of the DPA is that it also acts as Secretary for Rehabilitation International. Quentin Angus, Byron Buick-Constable and John Stott represented the DPA in RI forums and were actively involved in working for change to ensure the perspective of disabled people was incorporated (see Chapters 5 and 6).

In my research I asked the participants if they felt it was important for the DPA to continue involvement at the international level of the disability movement [Appendix 1]. All the participants indicated it was very important, even though this put extra financial pressure onto the DPA. In her interview Mary Stott stated she felt the DPA benefited from being able to draw from overseas experience, and Paul Gibson commented that:

*International involvement is important – just as individuals don't work best in isolation, neither do nations.*

In her interview Anne Hawker made the point that the DPA had a lot to contribute to the international arena, and in particular, in the Asian and Pacific region.

*DPA could play a greater role in DPI activities in the Asian-Pacific region... that there is respect for DPA, for New Zealand, and we have had significant roles in*

*terms of being peacemakers and being international model players... showing models that work and not being afraid to criticise.*

Earlier discussion (see Chapter 5) highlighted that many overseas commentators saw the DPA as being both unique and a world leader when it incorporated both RI and DPI. However, maintaining its membership with both these international organisations has created an inherent Constitutional conflict within the DPA. To qualify for membership of RI organisations must provide rehabilitation and disability support services, while DPI requires member organisations to have disabled people holding the majority. Therefore, in order to qualify for membership in both organisations the DPA Constitution requires both a majority of disabled people and a majority of corporate representatives (see Chapter 5). Rehabilitation International approaches disability issues from the service provider perspective, adopting a largely medical model approach, while Disabled Peoples' International is run by disabled people and promotes disability issues from the social model approach. Because of these differences these two organisations have been unable to work together cooperatively at the international level. In her interview Marilyn Baikie discussed the disbelief expressed by people overseas when she outlined how both the RI and the DPI merged into one organisation, the DPA.

*...The only way you'd ever get progress was for RI and DPI to be working against each other, to be bouncing off each other and be presenting the different ideas to government and so forth...*

However, the relationship within the DPA has had some considerable success, especially during the first decade, as Paul Gibson reflects in his interview.

*DPA is an organisation to be proud of. That we have included a more diverse group... I've got the privilege to be leading an organisation which because of what's come before me, because of the work which previous presidents, previous members of the Secretariat, have done is a world leader. We have made a difference and that has been particularly difficult given the agenda of governments in the last 14 years or so.*

There are now some significant tensions within the organisation, evidenced with the decrease in the numbers of 'corporate members' and individual members, and the confusion around the goals and objectives of the DPA, as discussed earlier in this

chapter. This confusion is inevitable, and it can be argued will be ongoing while the organisation continues to accommodate conflicting values represented within its membership of disabled people and service providers whose interests are not necessarily compatible with each other.

In her interview Anne Hawker recognised some of these tensions, stating that she believed it was important to

*...try to get the disability community to recognize that they don't lose anything by all of us working cooperatively... Service providers are part of DPA membership...*

However, she noted that:

*Some of them [service providers] are finding it hard to... commit to the philosophy of DPA.*

It can be argued that the ambivalence of some service providers to fully embrace the philosophy of the DPA can be partly traced to model set with right wing government policies that have been in place for the past 15 years. The emphasis has been on 'consulting' with 'consumer groups', where disabled people are often seen as passive recipients of support services and not capable of actively participating in decision-making processes. This is in total contrast to the analysis contained in the social model that sees structural and attitudinal barriers preventing disabled people from participating to their maximum potential, and not individuals' deficits.

Given that the RI and the DPI are at opposite ends of the spectrum in disability politics it is not difficult to see why the DPA is experiencing considerable internal tension as it continues trying to work within this uneasy partnership. Clearly the DPA wants to maintain some level of relationship with service providers. It is therefore essential that disabled people within the DPA and the wider disability movement clarify what the role of non-disabled people, including representatives of service provider organisations, needs to be, ensuring that the power base is clearly with disabled people. The future composition of the DPA's own membership will determine whether the organisation will maintain its membership with both Rehabilitation International and Disabled Peoples' International, and the level of involvement they will continue to have in the international arena.

### ***Issues Facing Disabled People Today***

In the final section of the interview participants were asked what they thought were issues facing disabled people today, and were invited to comment on aspects of the DPA that may have not been covered in the body of the interview [Appendix 1]. The following comments summarises the points that were raised.

A key issue for all the participants was for provisions under the Human Rights Act 1993 to be strengthened and to be extended into other legislation. Paul Gibson explained that:

*Human Rights is seen in New Zealand... by the [Human Rights] Commission and government... as purely to do with attitudes... Discriminating because of perceived cost-savings... when it comes to Human Rights people with disabilities have got the barrier of perceived costs, or short-term costs to overcome as well.*

In the Human Rights Act 1993 government departments were exempted from having to comply until the year 2000, but were required to review how Human Rights provisions would be implemented, ensuring that groups such as disabled people would not be discriminated against in the public sector. In 1999 government attempted to end this review process, known as Consistency 2000, and although the requirement has been retained, the participants identify that progress needs to be closely monitored.

Anne Hawker discussed how she would like to see Human Rights provisions extended further by implementing a programme based on a model used by Canada in their Human Rights legislation. Using this model, all legislation would be required to incorporate overarching principles that would ensure that economic independence (for individuals) is encouraged, and would ensure that access and participation for all citizens at all levels of society be encouraged.

Anne also discussed the inequities that exist in the levels of resources that different groups within the disability community are able to access. She highlighted differences in entitlements of those who receive personal income, funding for services and equipment through ACC and those who receive assistance through Income Support Services and Disability Support Services under the Ministry of Health. Historically the provisions through the ACC have been considerably more generous and more comprehensive than those through Social Welfare and Health, creating inequalities between those people who acquired impairments as a result of an injury and those

whose impairments are congenital or due to an illness. Anne argued that individuals and groups who have greater access to resources also have greater opportunities to actively participate at all levels of society.

Finally, Anne emphasised the need to encourage the development of services for Maori disabled people to be developed by Maori people. She argued that services for disabled people have been largely mono-cultural, with cultural needs and beliefs of people other than Pakeha New Zealanders not being appropriately addressed, and warns of a philosophical and cultural clash arising between Maori culture and disability culture. Anne believes it is important for the disability community to acknowledge the differences that exist within its membership (based on the differences between impairment groups as well as differences based on gender and sexual orientation, class, and race/cultural divisions). By recognising our differences, they are less likely to be used against us.

The participants focused on issues around bioethics as being important for disabled people to address. Paul Gibson stated that:

*There is a range of bio-ethical issues that have just arisen in society in the last few years, with changing technologies, which DPA has to keep up with. People with disabilities understanding has to keep up... because technology is moving at one speed, very fast... economics is going out in a tangent... and it's impacting on other areas but the actual understanding, social frameworks, moral frameworks from within which decisions are made isn't keeping pace. And we, people with disabilities, DPA, need to be a leader in this area.*

Anne also stressed the need for a disability perspective to be developed and widely promoted both within the medical community and in other political arenas. Questions around whose definition of 'quality of life' is being considered, and the availability of appropriate and adequate support services for disabled people need to be included when discussing options such as genetic engineering (for eradicating some disabling conditions) and euthanasia.

Other issues raised by the participants clustered around income support, education and employment. Marilyn Baikie talked about the need for attitudinal changes in order to create more opportunities for disabled people in these areas.

*We need to change the attitude towards people with disabilities, [for people to see] that people with disabilities are just people... With talents, skills and abilities...*

However, Anne believes a wider approach is required. She discussed the need for policy changes, moving away from victim blaming (which has been the government response to unemployment for the past 15 years). Anne argued that statistics such as the low participation in education and high unemployment rates for marginalised groups need to be recognised as having been created by economic mechanisms that are built into the structure of our society.

The disability movement as a social movement focuses on the elimination of social injustices and the assertion of Human Rights for all human beings. Issues such as those outlined above could be incorporated into an agenda for DPA and used as the foundation from which to set a direction to organise social and political action, and resume a leading role in the disability movement in New Zealand.

## **Conclusion**

Theoretical frameworks outlined in Chapter two emphasise the importance of unpacking discourses surrounding the marginalisation of disabled people. This involves analysing the conditions that dictate their lives and are socially constructed, and not accept these as part of a natural order. Using Foucault's analysis of power, opportunities for resistance at the micro and macro levels of society can be identified, and strategies can be developed to challenge current dominant models in relation to disability. These strategies for change need to include the deconstruction of language practices to look at how disabled identities are produced, and therefore how alternative images can be created.

This chapter has compared the analyses and approaches of the disability movements in New Zealand and Britain in challenging power relations that perpetuate dominant structures, knowledges and discourses and emphasise the needs and the achievements of non-disabled people. The research suggests that there has been a lack of ongoing debate within the disability movement in New Zealand, and particularly within the DPA, around definitions and analyses of disability, and what the fundamental principles are that should inform political and social action. It is suggested that there is very little understanding within the DPA or the wider disability movement in New Zealand of the

analysis contained in the Social Oppression Theory outlined by Oliver (1990). Activists in the British movement insist that it is crucial for the disability movement to have a clear analysis of disability in order to be clear on the issues when working for structural and attitudinal changes in society.

There is a great deal of pride within the DPA at having a diverse membership comprised of disabled people and service provider organisations. In contrast, the BCODP emphasises the importance of disabled people creating their own space to share their experiences and formulate a collective analysis of disability without being influenced by non-disabled people who not only work on their behalf, but also formed and promoted current dominant discourses that surround disability. It is argued that this approach enables disabled people to organise from a position of strength in challenging their marginalised position in society.

According to Abberley (1997), as well as reacting to their marginalisation the disability movement is also actively involved in consciousness-raising among disabled people and the wider society, and in the exploration and promotion of different cultural values and norms in relation to disability. In its efforts to survive as an organisation the DPA has become removed from the disability movement. Issues that face disabled people in New Zealand today were identified and briefly discussed by participants in my research and are highlighted in this chapter. They include concerns about inequities in incomes and service provisions for disabled people, the need for provisions contained in the Human Rights Act (1993) to be strengthened, and the need for a disability perspective to be incorporated in debates around bioethics and eugenics. These provide a potentially powerful agenda for the DPA and the wider disability movement to organise social and political action throughout the regions, raising the consciousness of disabled people and working for structural change. This process would allow disabled people to debate issues and relate their experiences to these issues, developing a critical analysis of disability.

## Chapter 9

### Conclusions and Recommendations

#### Background to My Thesis Topic

I made my decision to research the development of the Disabled Persons Assembly in the year the organisation celebrated its 15<sup>th</sup> Anniversary. I was aware that the development of the DPA had not been comprehensively researched and documented however preliminary inquiries revealed that the DPA had extensive archival material stored with the National Secretariat of the DPA in Wellington and in the Massey University Library. I was also aware that three key players in the DPA's development were deceased.

It was not my intention to provide a chronological account of the history of the DPA. Rather my research focus was to develop an understanding of the development of the DPA as part of the disability movement in New Zealand from the point of view of individuals who had been active in that movement.

#### Review of Methodology and Methods

The focus of my research was to develop an understanding of the development of the DPA as part of the disability movement in New Zealand from the point of view of the individuals who have been active in that movement. The objectives of the research were to:

1. Trace the development of the DPA in New Zealand
2. To locate this development in the wider picture of social/political and economic developments in New Zealand
3. To identify key people involved in the development of the organisation, and
4. To explore theoretical ideas that are useful in examining the experience of the DPA in particular, and the experiences of disabled people in general.

Archival records and publications, and the reflections and interpretations of events from the six National Presidents (or their surviving spouses) from 1983 to the present are used to develop an analysis of the development of the DPA.

The data is organised into the following themes:

- Historical overview of the DPA
- Philosophy, values and beliefs of the DPA
- Leadership (including individual profiles)
- Successes and ongoing issues for the DPA as part of the New Zealand disability movement
- Future directions

These themes provide the base for my chapters and a framework from which to present my discussion and analysis, and to relate my findings to relevant literature.

My research for this thesis was developed from the interpretivist methodology base. I was keenly aware that there was little material published written by disabled people that promoted an understanding of disability issues, and that accounts of the development of disability-related organisations in New Zealand had tended to be written by non-disabled people. I wanted to interview people who had a clear understanding of the beginnings of DPA and of the issues facing disabled people at that time. I decided to focus on the experiences of the National Presidents of the DPA since 1983 as they had been involved at different times during the organisation's history, provided a range of perspectives and interpretations of the development of the DPA, and were able to articulate the issues. This approach is consistent with theoretical frameworks I have used in my data analysis.

There have been six people who have held this position since 1983, three of whom have since died. In the situation where a past president has died, I approached the surviving spouse or family members to participate. They were asked to reflect on the involvement of their family member in the DPA.

I used qualitative research techniques, conducting interviews with the six National Presidents of the DPA (or their surviving spouses) since 1983. During the interviews I referred to a semi-structured interview schedule from which a range of topics were explored. This approach enabled the participants to share their personal knowledge and interpretations of events that occurred at different times during the organisation's history. In addition, the participants were asked to provide some biographical details as background to their interview. This provided an insight into the personal lives of

participants and to see how social, political and economic policies that impacted on their lives contributed to their individual perspective. The information was used in the analysis of the individuals' leadership approach during their term of National President of DPA.

Participants in this thesis are well known within the disability community. It was therefore quite possible that, if quoted, they could be identified. I was committed to using this thesis as a means to publicly acknowledge the contribution of people in the DPA's development. I sought their permission to quote directly from their interview and to have their quotes referenced to them by name.

In addition to the interviews I extensively referred to archival records from the DPA. The use of archival records is very important as part of the triangulation process in which other sources of information are used to verify the subject's story. They assisted me to verify the recollections of the participants or to examine any contradictions in the stories.

## **Review of Theoretical Frameworks**

In this thesis I have used theoretical ideas from Social Construction Theory, specifically key concepts and ideas from Michel Foucault's work on truth, power and knowledge, and Social Oppression Theory to explore the development of the DPA from 1983 to 1999. I have also examined the relevance of these theoretical ideas for making sense of the experience of disability.

These theories emphasise the importance of unpacking discourses surrounding marginalised groups such as disabled people, identifying how the conditions that dictate their lives are socially constructed, and not part of a natural order. I analyse the power relations (of which disabled people are involved) to highlight their struggles, and to identify points where resistance has occurred. By working through this process it is possible to identify strategies that can be used in the future by disabled people to bring about meaningful and lasting social and structural changes at the micro and macro levels of society.

In addition to these theories I have discussed the leadership styles of the National Presidents and then referred to a model drawn from organisational theory to examine the stages of the organisational life cycle the DPA has gone through in its development.

Using these two models, the challenges for the organisation, the responses of its leadership to these, and the subsequent adaptations made at the various stages of its development were analysed.

## **Review of Findings**

Discussion on the findings from my research begins with an historical overview of the DPA, including an examination of events that led to its formation. Key trends that informed various responses from governments and the voluntary sector to the needs of disabled people from early colonial times through to the early 1980s were outlined. The emergence of the DPA can be seen in the context of social and political developments at that time when groups were being formed and run by disabled people for disabled people. However, the data shows that the early leaders met with some considerable resistance from large service provider organisations to form an organisation that enabled disabled people to represent their own interests in the political arena. The emergence of the Disabled Persons Assembly in 1983 provided a focal point for the disability community from which to organise political action, and provided an opportunity for disabled people to build strength and unity amongst themselves.

The DPA is a national organisation. Its structure was intended to ensure that the balance of power within the organisation was with disabled people. Archival records show that at the inaugural DPA meeting in Hamilton in 1983 the fundamental principles from which the DPA now operates were first formulated. Those early leaders approached the task of establishing an organisation that would be recognised as “the speaking voice of the disabled” with determination, commitment and passion. They were clearly working for structural change.

However, an examination of the organisational structure raises questions around who the DPA represents and the potential conflicts of interest that exist between the various categories of the membership. I conclude that the requirement for both a majority of disabled people and a majority of corporate representatives on Regional Executive Committees and the National Executive Committee created an inherent constitutional conflict.

The six individuals who held the position of National President of the DPA had distinct leadership qualities and brought considerable talent, skills and knowledge to the

organisation. They came from a background of higher education and are recognised as being highly successful in their careers and community positions they held. All experienced the onset and/or deterioration of impairment later in their lives. They all had a strong sense that what impeded their ability to function and participate fully in society wasn't their impairments but rather the physical, social, attitudinal and political barriers confronted by disabled people daily. They all worked from a strong sense of social justice and were committed to working for change.

The early leaders were driven by the vision to establish the DPA as a strong organisation representing disabled people and their families, service provider organisations, and consumer groups. There were high-profile projects to provide the momentum, and people were excited about this new organisation that was seen to be radical in what it was setting out to do. Those early days were a time of innovation.

As the DPA became more established the emphasis from the later Presidents was for the consolidation of organisational structures and processes and its work in the wider community. The organisation began to encounter difficulties identifying people with the drive and skills to take on the leadership role in an organisation with such a diverse membership that was rapidly growing in size.

From the beginning the DPA has been seen as a unique and innovative organisation, providing the organisational structure for the disability movement in New Zealand. As well as working on social and political issues, the DPA has had to develop nationwide structures and systems to maintain its membership. I have identified stages of development the organisation moved through as it became better organised and formalised its structures in order to manage and coordinate its activities. This has created tensions for the organisation, as its leaders have had to balance the goals of the disability movement for social and political change with the need to develop its organisational systems and structures.

The DPA was instrumental in pioneering two revolutionary services, Total Mobility and Teletext, which were initially administered by the DPA but are now integrated into mainstream public services. Another successful campaign was for the inclusion of disability in anti-discrimination legislation. The inclusion of disability in the Human Rights Act 1993 has provided a platform from which people as of right can demand the removal of barriers, both structural and attitudinal.

A prominent theme is that the Disabled Persons Assembly has been a focal point for the disability movement in New Zealand, and provided it with an organisational structure. Part of this discussion referred to international influences on the disability movement in New Zealand. I compared the development of the British Council of Disabled People with that of the DPA. The British experience illustrates the importance of having disabled people working together to develop an analysis of disability and an agenda for structural change. My discussion and analysis of the DPA philosophy and structures concluded that there is not a clear understanding and analysis of disability. This has resulted in the membership and its leaders being unclear about their vision of the 'ideal society'.

Finally, some of the main issues that face disabled people in New Zealand today, as identified by the participants, were discussed. These issues included concerns about inequities in incomes and service provisions for disabled people, the need for Human Rights provisions to be strengthened, and the need for differences within the disability community to be recognised and incorporated in the development of policies and services.

## **Conclusion**

This has been an opportune time to reflect on the development of the DPA. In this thesis the development of the DPA over the past sixteen years is charted, based on the recollections of individuals who have been active in that movement. It has grown from a fledgling organisation with a vision to bring about change for disabled people, into a national organisation that is recognised by government departments and local bodies throughout New Zealand as promoting the interests of disabled people, their families, and service provider organisations. The DPA has provided a focal point and an organisational structure for the disability movement, and has initiated several successful projects that have significantly impacted on the lives of disabled people. It is important for any organisation involved in political and social action to review its history, celebrating its successes while acknowledging the work still to be done. The DPA has many issues and challenges to confront if it is to survive and grow, but this research shows that the organisation has a key role in contributing to processes that enable disabled people to decide and determine their own future.

## Recommendations

The research has shown that the DPA is at a turning point. There are significant issues to resolve if the DPA is not only to survive, but also to grow and continue to be instrumental in advocating for structural changes in society to achieve full citizenship for disabled people in New Zealand.

A prominent principle identified in this thesis is the power of language and disability. In my discussion on the DPA's organisational structure, philosophies and values I argued that the definitions and analysis (and therefore, the language used) of disability used within the DPA are unclear and often contradictory. The British experience shows that the development of a critical analysis strengthens the position of the organisation, providing clarity in its goals and objectives and enabling disabled people to set a clear political agenda to work for change. **The DPA therefore needs to take a leading role in encouraging debate led by disabled people to develop an analysis of disability.** This would put the DPA and its membership in a stronger position to challenge the marginalised position of disabled people in society and build resistance against the dominant discourses surrounding disability that currently prevail.

The DPA provided the formal organisational focus for the disability movement in New Zealand, especially during the 1980s and early 1990s. However, my analysis suggests that from 1993 onwards the organisation's focus has been more on the development and maintenance of its infrastructure in order for its survival, with particular emphasis on policy development at the National Executive level. In focusing more on infrastructure it appears the DPA has become isolated from the wider disability movement. **The challenge for the leadership in 1999 and beyond is to determine what its continued role within the disability movement will be, while still developing and maintaining its own organisational structures.**

In 1999 the National Executive Committee began a review of the DPA's Constitution. I have argued that as part of this review **it is crucial that the DPA address the composition of its membership.** At present the Constitution requirement is that the majority of the organisation's membership be disabled people, and for both a majority of disabled people and a majority of corporate representatives on Regional Executive Committees and the National Executive Committee. These requirements entitle the DPA to have membership on two international bodies, Rehabilitation International and

Disabled Peoples' International. It was argued that such an arrangement would encourage corporate member organisations to nominate disabled people as their representatives. However, I have argued that this situation creates an inherent Constitutional conflict of interest as the organisation attempts to balance the needs of disabled people, their families, and those of the corporate member organisations.

Given that Rehabilitation International and Disabled Peoples' International are at opposite ends of the spectrum in disability politics it is not difficult to see why the DPA is experiencing considerable internal tension as it continues trying to work within this uneasy partnership. Clearly the DPA wants to maintain some level of relationship with service providers. **It is therefore essential that disabled people within the DPA and the wider disability movement clarify what the role of non-disabled people, including representatives of service provider organisations, needs to be, ensuring that the power base is clearly with disabled people.** The future composition of the DPA's own membership will determine whether the organisation will maintain its membership with both Rehabilitation International and Disabled Peoples' International, and the level of involvement they will continue to have in the international arena.

The challenge for the organisation and its leaders is to ensure innovation is encouraged in the planning processes in order to achieve DPA goals, and to encourage its continued growth and development. Participants of this study identified a wide range of issues that face disabled people in 1999 and beyond. These issues impact directly on the rights of disabled people, and present barriers to their active participation in their communities. **The DPA therefore needs to take a leading role in addressing current issues facing disabled people, initiating action on these issues at the local grassroots level as well as at the National level.** By focusing on issues that profoundly impact on disabled people opportunities are created for the DPA and the wider disability movement to organise social and political action locally and nationally, and to use their experiences to contribute to action in the international arena.

## APPENDIX 1: INTERVIEW SCHEDULE

### INTERVIEW SCHEDULE

#### SECTION A Introducing DPA

In this section I would like you to reflect on your (or your spouse's) view of DPA... how you would describe DPA.

1. What was your understanding of DPA as an organisation when you first joined? Why did you (or your spouse) join?
2. What would you identify as being the key philosophies that best identified what DPA stood for when you (or your spouse) became President?

#### SECTION B Involvement in DPA and Presidential Work

In this section I would like to explore your (or your spouse's) involvement in DPA and move into your work as President.

3. Can you give me an overview of your (or your spouse's) involvement within the disability community or your work on disability issues that led to your involvement in DPA (or before the establishment of DPA)?
4. Can you tell me about your (or your spouse's) time as National President of DPA... describe the sort of work that you were doing.
5. Can you tell me the hopes and plans you (or your spouse) had that made you want to take on the role of President?
6. Can you tell me about both the highlights and low points of your presidency? (achievements and disappointments).

#### SECTION C Leadership Style

In this section I would like to spend some time reflecting on leadership issues in DPA.

7. How would you describe your (or your spouse's) leadership style?
8. How do you think members would have described your (or your spouse's) leadership style?

#### SECTION D Current Philosophy of DPA

In this section I would like to explore current key themes and philosophies of DPA.

9. Discuss what new philosophies and belief systems you think are evident in DPA today? Do you think this philosophical base is useful in setting an appropriate direction for DPA? Do you think these philosophies best reflect the needs of disabled people in New Zealand as we approach the year 2000?
10. What do you see as the main issues facing disabled people today that DPA needs to be addressing?

#### SECTION E Future Directions

In this final section I would like to explore possible future directions for DPA.

11. Throughout this interview I have been working on the implicit assumption that there is a future role for DPA... do you think DPA is still needed? If yes, what role(s) do you think the organisation has? If no, why not?

12. DPA has had significant involvement in the international disability movement... do you see this as having been important? If yes, do you think it will continue to be so? If no, explain why you do not think they should have had an international presence.

13. Do you think there has been an agenda (either implicit or explicit) of presenting a particular "image" of disability? If yes, what do you think this image has been, and do you think it still exists today? What implications do you think there might be if this image continues to be presented? What do you think DPA might need to do to change this (if you think it needs to change)?

### **SECTION F Conclusion**

In this conclusion section I invite you to make any further comments regarding DPA and the needs of its diverse membership that might not have been covered thus far.

Thank you for your participation.

## APPENDIX 2: LETTER OF INVITATION

4 July 1998

Dear

I am currently enrolled at Massey University in the Masters in Social Work through the School Of Policy Studies and Social Work. I have chosen as my thesis topic to research the development of the Disabled Persons Assembly (New Zealand) Inc. Enclosed is an Information Sheet, which outlines my project in greater detail.

In preparation for this project I have been liaising with Dave Henderson at the National Office of DPA, and it is through him that I was given your address. I am approaching you with an invitation to participate in this project, as I am interested in exploring with you your views and impressions of your involvement in DPA, particularly in your current role as President.

I will contact you by telephone within the next two weeks to discuss my project with you further, and to answer any questions you may have. Please do not hesitate to contact me in the meantime if you wish.

I look forward to talking with you soon.

Yours sincerely,

Sara Georgeson

## APPENDIX 3: INFORMATION SHEET

### INFORMATION SHEET

#### Introducing Myself

My name is Sara Georgeson and I am doing this research project for my Masters in Social Work thesis. I am an individual member of DPA, and have had significant involvement in the movement since its inception in 1983. As a disabled woman I have a particular interest in addressing the issues for disabled women. I have been particularly involved in my Regional DPA, holding a range of positions in the Regional Executive (Palmerston North & districts), including women's coordinator, Vice-President, and more recently, President. The National Executive of DPA is supporting my project. Inquiries can be directed to Dave Henderson, Chief Executive Officer for DPA, P. O. Box 27524, Wellington, Phone (04) 8019100.

I am being supervised in this project by two senior lecturers, Mary Nash and Mary-Ann Baskerville. They can be contacted at the School of Policy Studies and Social Work, Massey University, Private Bag, Palmerston North, phone (06) 3569099.

#### How can you contact me?

I work part-time at the Manawatu Polytechnic in Palmerston North as their Disability Coordinator. If you need to, you can contact me at work **phone (06) 3500010 ext. 8276**. Otherwise you can contact me at home **phone (06) 3574277**. My postal address is **412 College Street, Palmerston North** and my e mail address is **Sara.Georgeson.1@uni.massey.ac.nz**

#### Nature and purpose of this project

I propose to research the development of organisation, the National Disabled Persons Assembly DPA (New Zealand) Inc and I invite you to participate in this project.

It is my belief that it is an opportune time to reflect on the progress of DPA as a National "umbrella" organisation that purports to be the "speaking voice of the disabled" and to reflect on the key principles for DPA. Have these principles changed since 1983? With the political and financial pressures currently facing DPA it is important to review its history and to re-evaluate their current position in order to begin to identify possible future directions. I hope to identify key trends in relation to the processes DPA has gone through in establishing themselves as a credible organisation and as having a significant leadership role within the disability community. I believe this is also an important opportunity to acknowledge the people who have been involved in DPA's development and to locate people with disabilities rightful position in New Zealand's history, to recognise that their contribution is not just within the disability community but in New Zealand society as a whole.

## **What is involved if you decide to participate?**

If you decide to participate in this project you will be involved in a semi-structured interview conducted by myself that will go for no longer than two hours. You will be asked to provide some brief biographical details of yourself (or your spouse). The interview is designed to explore your contribution as National President of DPA (or that of your spouse), to map the development of DPA since 1983 and to identify key trends within that time. It is also an opportunity to identify issues that exist for DPA as an organisation, and for disabled people in New Zealand. I will phone you shortly after you have received this information sheet to discuss the project with you further and to answer any questions you may have. With your permission, this interview will be audiotaped. A transcript (written account) of the interview would then be sent to you to review for accuracy.

## **Anonymity and confidentiality**

I believe an important component of this project is to recognize and acknowledge the work of key figures in DPA both in the disability movement and the wider society of New Zealand. I will therefore ask that you complete an initial consent form, and then indicate on a second form (that will specifically relate to the use of information from your audio-taped interview) your permission to a) identify you as a participant of this project and b) to reference quotes made by you during the interview. I undertake to work with you as I write up the project to ensure accuracy of the information in the final report.

As part of the transcription process, I will require the person who transcribes the tapes to sign a confidentiality agreement.

## **Your right to decline to take part**

I undertake to give you a typed copy of your interview that you can check for accuracy, and which we can discuss further, if required.

I encourage you to ask any questions you might about the project, at any time during the project. I am committed to discussing any concerns that might arise for you, and to working with you to change aspects relating to your input, as appropriate. You are free to withdraw from the project at any time.

I hope you will consider participating in this project and I will phone you in the next couple of weeks to discuss the project through with you further.

Sara Georgeson

## APPENDIX 4: BIOGRAPHICAL INFORMATION SHEET

**BIOGRAPHICAL INFORMATION***(Background to interview)***Name****Date of Birth****Nature of Disability****Educational Background** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Work History** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Current Occupation****Date/Year of joining DPA****Term of Presidency**

## APPENDIX 5: CONSENT FORM

**CONSENT FORM**

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that she might quote me, and that I can work with the researcher to ensure accuracy of the information used. The information will be used only for this research and publications arising from this research project.

I agree/do not agree to the interview being audio taped.

I also understand that I have a right to ask for the audiotape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signed:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## APPENDIX 6: CONSENT FORM FOR USE OF INFORMATION

**Guidelines for the Use of Information from Taped Interview  
Between:**

Interviewer: Sara Georgeson  
and  
Respondent: [Name]

Please circle your response

1. I am willing to be identified by name and position as being interviewed for this research. yes/no
  
2. I am willing to be quoted by name from the transcript of my taped interview. yes/no

If you answered "No" to question 2 please answer question 3.

3. I am willing for quotes from my transcript to be used so long as I remain anonymous. yes/no

Signed: \_\_\_\_\_

## APPENDIX 7: CONFIDENTIALITY AGREEMENT

**CONFIDENTIALITY AGREEMENT**

I \_\_\_\_\_ agree to maintain confidentiality in relation to any material I might type for Sara Georgeson in relation to her Masters in Social Work thesis, including the transcription of audiotaped interviews.

**Signed:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## APPENDIX 8: CONSTITUTION of DPA (NZ) Inc

# Constitution and Rules of Disabled Persons Assembly (New Zealand) Incorporated

## Table of Contents:

1. Name
2. Objects
3. Powers
4. Membership
5. National Executive Committee
6. Administration and Powers of the National Executive Committee
7. General Meetings of the Assembly
8. Notice of Meetings and other Notices
9. Procedure at Meetings and Voting
10. Regional Executive Committees
11. Regional General Meetings
12. Eligibility of National Executive and Regional Executive Committee Members
13. Funds, Property and Subscriptions
14. Common Seal
15. Alteration of Rules
16. Dissolution
17. Registered Office

May 1994

## 1. NAME:

The name of the organisation shall be DISABLED PERSONS ASSEMBLY (NEW ZEALAND) INCORPORATED. (In this Constitution and Rules called, 'the Assembly').

## 2. OBJECTS:

The objects of the Assembly shall be:

1. To promote in every way in New Zealand the interests and welfare of all people with disabilities and in particular:
  1. To encourage and promote full participation and equal opportunity for all people with disabilities in the normal life of the community; to promote self-help and independent living among them and to ensure that adequate services are provided to achieve these objectives; to promote the right of

- people with disabilities to self determination, dignity, acceptance of challenge, citizenship and full access to public amenities.
2. To facilitate the participation of all people with disabilities in the design, formulation, implementation and evaluation of policies, programmes and services for their needs and to monitor, evaluate and review such services.
  3. To encourage and promote coordination of all services and programmes intended for people with disabilities whether provided by agencies for people with disabilities, organisations of people with disabilities, local coordinating councils, Government Departments, the Accident Compensation Corporation, hospitals, schools, professional bodies, entities and individuals.
2. To advocate the rights and needs of people with disabilities at national and international levels in order that they may enjoy their rightful share of society's resources, benefits and responsibilities and to serve as a representative voice for people with disabilities and organisations engaged in the field of services to people with disabilities; to monitor legislation and rulings pertaining to people with disabilities and make submissions when appropriate; to develop an informed public opinion about and stimulate community interest in people with disabilities.
  3. To provide the exchange and dissemination of information relevant to people with disabilities; to assist in the provision of aids and information centres; to provide assistance to people with disabilities having communication difficulties and to provide communication links with people who because of disability are homebound; to make available information about disability, its treatment, correction and prevention.
  4. To promote effective measures for the prevention of disability and rehabilitation from disabling conditions.
  5. To serve as a consultative body to Government and other organisations engaged in the field of services to people with disabilities; to promote or undertake research in any aspect of habilitation or rehabilitation; to organise training courses for people concerned with programmes for people with disabilities; to organise conferences, seminars, study groups or workshops on subjects relevant to people with disabilities.
  6. To affiliate with international bodies or other organisations having similar purposes and, in particular, to affiliate with Rehabilitation International, a global body with broad areas of concern in the rehabilitation field; and to affiliate with the Disabled Peoples' International, an international body having a particular concern that people with disabilities have a right to full participation and equality and the right to share in the normal social life of the community and to promote the objectives of recognised international charters, manifestos and programmes including the promotion of the Rehabilitation International Charter for the 1980's and the Disabled Peoples' Charter.
  7. To do all such other things as are incidental or conducive to the attainment of any of the above objects.

### **3. POWERS:**

The Assembly shall have all the powers conferred by the Incorporated Societies Act 1908 or implied by law including but without in any way limiting such powers the power: -

1. To purchase, acquire, lease, exchange, sell or otherwise deal in real and personal property of any kind and to erect and maintain buildings.
2. To accept subscriptions and donations whether of real or personal property, devises and bequests for all or any of the purposes of the Assembly and to take or hold property subject to any trust and to deal with such property as allowed by law having regard to such trust.
3. To invest and deal with any of the monies or other assets of the Assembly, not immediately required upon such securities as the National Executive Committee may from time to time determine or approve.
4. To obtain professional services and to employ, engage and discharge agents or servants.
5. To affiliate with, subscribe or donate to, or become a member of, any other body whose objects are substantially similar to those of the Assembly.
6. To borrow or raise money in such manner as the National Executive Committee may think fit for any of the objects of the Assembly and, in particular, by the issue of debentures, mortgages or other securities charged upon all or any of the Assembly's property, both present and future.
7. To apply the funds of the Assembly in promoting or furthering all or any of the objects of the Assembly with power to do all such other things as are incidental or conducive to the attainment of the objects of the Assembly.

### **4. MEMBERSHIP:**

1. Membership of the Assembly shall comprise the following categories:
  1. Corporate Membership
  2. Individual Membership
  3. Family Membership
  4. Associate membership (Corporate or Individual)
2. Corporate Membership:
 

Any society, association or other body of persons whether corporate or non-corporate which is a non-profitable, charitable or welfare organisation, whose objects are similar to the objects of the Assembly or who work in any way for the benefit of people with disabilities, may apply in writing to the National Executive Committee for admission as a Corporate Member. If a majority of the National Executive Committee vote in favour of the application such society, association or other body of persons shall be admitted as a Corporate Member.
3. A single society or organisation having regional or branch divisions shall with the agreement of the National Executive Committee be entitled to separate Corporate Membership of the Assembly and representation at General Meetings for itself and for each of its local branches and regional structures. Where a

Corporate Member by itself, or any of its branches, provides services in more than one region established by the Assembly under Rule 10, such a member may be represented at Regional Assemblies for those regions and its representatives shall be eligible to serve on Regional Executive Committees. Where a single society has multiple Corporate Membership, the National Executive Committee may cancel or reduce such membership in respect of any branch or regional structure which, in the opinion of the National Executive Committee has ceased to be active.

4. Individual Members:

Any person whether they have a disability or not, may apply in writing to the Regional Executive Committee for the region in which that person resides to be admitted as an Individual Member and if a majority of the Regional Executive Committee vote in favour of the application, the applicant shall be admitted as an Individual Member of the Assembly PROVIDED THAT at all times the majority of Individual Members in the Region shall be people with a disability or the parent or guardian of a person with a disability. Individual Members may be admitted to membership by any Corporate Member acting pursuant to Rule 10(e) or if there be none by the National Executive Committee.

5. Family Members:

Two or more members of a family may apply together in writing to the Regional Committee for the Region in which the family resides, to be admitted to Family Membership. If a majority of the Regional Executive Committee vote in favour of the application, the applicants shall be admitted to Family Membership of the Assembly. Family Membership may also be granted by any Corporate Member acting pursuant to Rule 10(e), or if there be none, by the National Executive Committee.

Admission to Family Membership of the Assembly shall entitle the member family to two votes in the affairs of the Assembly, with two individual names being put forward by the family for recording by the Assembly. The subscription for Family Membership shall be equivalent to one Waged and one Unwaged Individual subscription or alternatively to twice the Unwaged Individual subscription rate, to be chosen by the family according to their circumstances.

6. Associate Members:

Any person, society, association or other body whether Corporate or Non-Corporate who is interested in the work and activities of the Assembly and desires to be associated with it, may apply in writing to the National Executive Committee (in case of Corporate organisations) or the appropriate Regional Committee (in the case of individuals) to be admitted as an Associate member and, if a majority of the appropriate Committee vote in favour of the application, the applicant shall be admitted as an Associate Member of the Assembly.

7. Any member of the Assembly may resign by giving notice in writing to the National Executive Committee in the case of Corporate or Corporate Associate Members, or their Regional Executive Committee in the case of Individual Members.

8. All members shall pay such annual subscription as shall be determined at the National Annual General Meeting. Corporate and Corporate Associate Members subscriptions shall be payable to the National Executive and Individual

- Members to their Regional Executive. Any member whose subscription is two years in arrears may be removed from the Register of membership by resolution of the National Executive Committee. A member shall be considered to be financial for the period for which the subscription has been paid.
9. Any member may be called upon to resign if there is any reason to believe that the member has been guilty of, or party to conduct contrary to these rules or inimical to the objects or interests of the Assembly. Before a member's resignation is called for, under this section, the member shall be given notice in writing by the National Executive Committee of the matters charged against the member and shall be given a reasonable opportunity of being heard in defence. Such notice in writing may be served by delivery in person or by mail to the last known mailing address by registered post. If no response is forthcoming within four weeks of a notice so delivered, then by direction of the National Committee, the member's name shall be removed from the register.
  10. The removal or resignation of a member shall not be a release from antecedent liability to the Assembly.
  11. Notwithstanding anything in this Constitution and these Rules, the Assembly shall at all times respect and preserve the Rules and constitutions of its member bodies and the autonomy thereof.

## **5. THE NATIONAL EXECUTIVE COMMITTEE:**

1. The National Executive Committee shall be the governing body of the Assembly and may exercise all its objects and powers not required by these rules to be exercised in General Meeting and shall consist of the following:
  1. A President and Vice President both of whom shall be ex-officio members of all sub-committees and Regional Executive Committees;
  2. Eleven committee members elected by rotation in the manner described below but so that of the total membership, including the President, Vice President and immediate Past President, the majority shall be people with disabilities (or the parents or guardians of people with disabilities) and the majority shall also be representatives of Corporate Members.
  3. The National Executive Committee may appoint a National Maori Advisor as a fully participating member of the Committee for a term not exceeding two years.
2. One of the members of the National Executive Committee other than the President and Vice President, shall be appointed by the National Executive Committee to represent the interests of people who are homebound.
3. Only Individual Members, Family Members or representatives of Corporate Members shall be eligible for the National Executive Committee. All members of the National Executive Committee shall be subject to retirement by rotation and shall be elected by postal ballot prior to the Annual General Meeting of the Assembly. No person shall be nominated as a member of the National Executive Committee unless written notice of such nomination supported by written acceptance by the nominee shall have been given by a corporate or individual member not less than eight weeks before the Annual General Meeting of the

Assembly. Such notice shall, except in the case of existing members of the National Executive Committee contain biographical details of the nominee and a statement as to whether or not the nominee has a disability and, if appropriate, the Corporate Member represented by the nominee. The postal ballot shall be conducted in accordance with Rule 5(e).

4. At the Annual General Meeting in each year 5 committee members shall retire from office. Those to retire shall be those who have been longest in office since their last election and as between committee members who were appointed at the same time those to retire shall (unless they otherwise agree among themselves) be determined by lot. A retiring committee member shall be eligible for re-election.
5. The postal ballot for the President, Vice President and retiring committee members shall be conducted by the Chief Executive Officer of the Assembly as Returning Officer and two scrutineers to be appointed by the National Executive Committee. The Returning Officer shall send voting papers to eligible voters at least one month before the Annual General Meeting. The voting papers shall include a summary of the biographical details of the nominees, the Corporate Members (if any) represented and whether or not the nominee has a disability. Voting papers shall be returned to the Returning Officer and any voting paper received after 5.00pm on the third day before the Annual General Meeting shall be invalid. The scrutineers shall count the votes and advise the result, in writing, to the Returning Officer for declaration at the Annual General Meeting. The scrutineers shall ensure that the committee members declared elected contain the requisite majority of people with disabilities and representatives of corporate members pursuant to Rule 5(a)(ii) by giving (if necessary) precedence to lower polling qualified candidates needed to constitute the requisite majorities.
6. The National Executive Committee may fill any casual vacancy occurring during the year but any member so appointed shall (if necessary) be qualified so as to retain the majorities required by Rule 5(a)(ii) and hold office only until the next Annual General Meeting.
7. The National Executive Committee shall meet at least three times in each year and more frequently if considered necessary. The President shall convene the meeting of the National Executive Committee within 30 days of receiving a written notice to do so from at least four members of the National Executive Committee.

## **6. ADMINISTRATION AND POWERS OF THE NATIONAL EXECUTIVE COMMITTEE:**

The National Executive Committee shall be the managing authority for all matters connected with the affairs of the Assembly and shall carry out the aims, objects and interests of the Assembly and without affecting the scope of its power, shall have authority to: -

1. Appoint such staff as it shall consider appropriate to constitute the Secretariat of the Assembly and to carry out all or any of the functions of Chief Executive Officer, Secretary/Treasurer and fix the terms of their appointment.

2. Establish and define the boundaries of Regional Assemblies and define and control the duties, powers and obligations of the Regional Executive Committee of those Regional Assemblies.
3. Make, alter and rescind by resolution, working by-laws and regulations to control and regulate:
  1. the administration of Regional Assemblies and their Regional Executive Committees.
  2. meeting procedures to be adopted by Regional Assemblies and their Regional Executive Committees.
  3. all other matters specified or involved in the aims and objects of the Assembly or in these rules provided however, that such by-laws shall be subject to and shall not conflict with the provisions of these rules.
4. Deal with any breach of rules or any misconduct on the part of Regional Assemblies or their Regional Executive Committee and hear and adjudicate upon any appeal against any of their decisions.
5. Define the authority of Regional Executive Committees to enter into financial commitments on behalf of the Assembly and the manner in which Regional Executive Committees shall administer financial matters.
6. Inspect the books and financial records of any Regional Executive Committee and generally do any act or thing in respect of any Committee which a principal may do in respect of an agent.
7. Carry out the functions and powers of a Regional Executive Committee in any region where no properly constituted Regional Executive Committee exists or in respect of which powers of a Regional Executive Committee have been suspended by the National Executive Committee.
8. Enter into contracts on behalf of the Assembly and expend the funds of the Assembly in carrying out its work and objects.
9. Appoint such sub-committees as it considers necessary and delegate any of its powers to any such sub-committee.
10. Institute or carry out or defend legal proceedings when necessary including the recovery of any debts due to the Assembly.
11. Establish and administer a communications bureau to facilitate links with people who because of disability are homebound using, as far as possible, electronic and other modern communication facilities to establish contact on a regular basis with people, who will be prevented by disability from attending meetings of the Assembly, its Regional Executive Committees or constituent organisations.
12. Carry out and enforce any of the other aims, objects and interests of the Assembly.

## **7. GENERAL MEETINGS OF THE ASSEMBLY:**

1. The Annual General Meeting of the Assembly (to be known as the National Assembly) shall be held not later than the 30 November in each year, at such time and place as is determined by the National Executive Committee.

2. An Auditor who is a member of the New Zealand Society of Accountants and not a member of the National Executive Committee or any Regional Executive Committee shall be appointed annually at the annual general meeting of the assembly.
3. A Special General Meeting of the Assembly may be convened by the National Executive Committee and shall be convened upon receiving a request to do so from not less than 20 members. The requisition shall state the objects for which the meeting is requested and shall be signed by the requisitionists and deposited at the registered office of the Assembly. Such a meeting shall be held within 30 days of the receipt of the request.

## **8. NOTICE OF MEETINGS AND OTHER NOTICES:**

1. Notice of all meetings shall be given to all members specifying the date, time and place of the meetings and the nature of the business to be dealt with. The following periods of notice shall apply:
  - Annual and General Meetings of the Assembly - 30 days
  - National Executive Committee and Regional Assemblies - 14 days
  - Regional Executive Committees - 7 days
2. At Annual or Special General Meetings of the Assembly and of Regional Assemblies no business except routine business shall be dealt with, unless such business shall have been specified in the Notice of Meeting or it is so agreed by a majority of the members present. The consideration of the Annual Report and Financial Statements and the Election of Officers and the Auditor shall be deemed routine business.
3. Notice of any meeting may be given by sending it to a member's last known postal address, or in the case of regional committees, by advertisement in a newspaper circulating in the district. The accidental omission to give notice of a meeting to any person shall not invalidate the proceedings at that meeting.
4. Any notice to be given to the Assembly or the National Executive Committee may be delivered personally to the registered Office of the Assembly or by posting it by registered letter addressed to the registered office. Any notice to be given to a Regional Assembly may be delivered personally to the President or any member of the Regional Executive appointed for the purpose.

## **9. PROCEDURE AT MEETINGS AND VOTING:**

1. A Corporate Member may appoint one representative to speak and to vote on its behalf at all General Meetings of the Assembly and Regional Assemblies. Corporate Members shall endeavour to appoint a person with a disability or the parent or guardian of a person with a disability as their representative. Written notice of the appointment of a representative shall be given by each Corporate Member to the Assembly and the Regional Assembly and shall state whether the representative has a disability or is the parent or guardian of a person with a disability. Such notice shall be deposited not less than 24 hours before the meeting at which the representative proposes to take part or vote and the

appointment shall remain in force until notice of another appointment is given by the Corporate member.

2. Family Members shall appoint two representatives to vote on behalf of the family at all General Meetings of the Assembly and Regional Assemblies. Written notice of the appointment shall be given by each Family Member to the Assembly or the Regional Assembly not less than 24 hours before the meeting at which the representatives propose to take part or vote and the appointment shall remain in force until notice of another appointment is given by the Family Member.
3. Quorum: The following number of members shall constitute a quorum at all meetings:
  - National Annual and General Meetings of the Assembly, 20 voting members attending by their representative or individual members present in person or by proxy.
  - Regional Annual and General Meetings - 7 members.
  - National Executive Committee and Regional Executive Committees - a simple majority of the members of such Committees.
4. If, within half an hour from the time appointed for any General or Committee Meeting, a quorum is not present, the meeting, if convened upon a requisition shall be dissolved but, in any other case, shall stand adjourned to such other day within fourteen days and at such other time and place as the Executive Committee may determine. If within half an hour from the time so appointed for an adjourned meeting a quorum is not present, any four members entitled to vote who are present in person or in the case of a Corporate Member, by its representative, shall be a quorum and may transact the business for which the meeting was called.
5. Voting at General Meetings of the Assembly and Regional General Meetings shall be by the voices or by show of hands except for the election of officers, when the voting shall be by ballot. In other cases voting shall be by ballot if demanded by any four members. The President or, in his/her absence, the Vice President or if both are absent, a member appointed by the meeting shall preside at all General Meetings and shall have a deliberative and, in the case of an equality of votes, a casting vote also.
6. At any General Meeting of the Assembly or any Regional Assembly each Corporate Member shall have one vote which shall be cast by its representative and each Individual Member or their proxy shall have one vote. Family Members shall be entitled to two votes at any General Meeting of the Assembly or any Regional Assembly.
7. Associate Members who are organisations may appoint one person to take part in discussion on its behalf at General Meetings and Individual Associate Members shall also be entitled to speak but no Associate Member shall have any power to vote.
8. No member shall be entitled to vote at any General Meeting or in any postal ballot unless currently financial at the time of the meeting or of the ballot.
9. At National Executive and Regional Executive Committee meetings each member shall have one vote. The President or, in his/her absence, a member

appointed by the meeting shall preside at all National Executive and Regional Executive Committee meetings and shall have a deliberative and, in the case of an equality of votes, a casting vote also.

10. An Individual or Family Member may appoint a proxy by depositing a written appointment with the Assembly, not later than the commencement of the meeting or adjourned meeting for which the proxy is intended to be appointed. The proxy may be in the following or similar form: -

- I, (name) of (address) being a member of the Disabled Persons Assembly (New Zealand) Incorporated hereby appoint (name) of (address) as my proxy to the General Meeting of the Assembly to be held on the day of, 19 and at any adjournment thereof.  
Signed this day of 19 .

This proxy is to be used:

- as the proxy thinks fit
- in favour of remits/motions numbered
- against remits/motions numbered
- in the event of any amendment to any remits/motions then as my proxy shall think fit

(Amend or complete as necessary).

A proxy for any Regional General Meeting may be appointed in the same way.

11. Any members of the National Executive Committee or any Regional Executive Committee having any interest in a contract or arrangement proposed to be entered into by the Committee shall declare that interest prior to the contract or arrangement being approved or entered into and having declared such interest the member concerned shall not be disqualified from speaking or voting in respect of such contract or arrangement.

## **10. REGIONAL EXECUTIVE COMMITTEES:**

1. To facilitate the coordination of the work of the Assembly at local level the National Executive Committee after consultation locally may divide the country into regions and define the boundaries of each region.
2. In each region there may be a Regional Executive Committee elected by the Corporate and Individual Members within the Region. A Regional Executive Committee of a region shall consist of a President, Vice President and Secretary/Treasurer elected annually and such number of Committee members, being not fewer than 4 or more than 11, as the Regional Assembly shall decide.  
The total membership of the Regional Executive Committee including the President, Vice President and Secretary/Treasurer shall have a majority of people with disabilities (or the parents or guardians of people with disabilities) and a majority of representatives of Corporate Members.  
Casual vacancies arising during the year may be filled by the Regional Executive Committee. Members of the National Executive Committee shall be entitled to attend Regional Executive Committee meetings.

3. Regional Executive Committees shall be vested with such powers and duties as shall be delegated to them from time to time by the National Executive Committee. Regional Executive Committees shall not enter into any financial commitment or obligation except to the extent and within the limits from time to time authorised by the National Executive Committee.
4. The Auditor of the Assembly shall have the right of access at all times to the books, accounts, minutes and other records and papers of any Regional Executive Committee and shall be entitled to require from the Regional Executive Committee such information and explanations as he/she thinks necessary in the interests of the Assembly.
5. Notwithstanding anything to the contrary in these rules the National Executive Committee may vest its function of coordination at a local level in any Corporate Member which is active in coordination in any region and delegate to such member such powers and duties as shall be necessary from time to time to facilitate the coordination of the work of the Assembly at local level within that Region.
6. In addition to the responsibilities and duties generally described in Rule 10(c), Regional Executive Committees have a specific duty and responsibility to maintain a register of their local membership, to issue receipts for all subscriptions, and to issue membership cards to new members.

Full details of such transactions shall be forwarded on a regular basis in a format and at intervals as shall from time to time be authorized and requested by the National Executive Committee.

## **11. REGIONAL GENERAL MEETINGS:**

1. An Annual General Meeting of a Region shall be held not later than 31 October at such time and place as shall be fixed by the Regional Executive Committee.
2. At the close of every financial year which shall be 30 June, each Regional Executive Committee shall prepare a full and complete Statement of Accounts and Balance Sheet which after being audited and adopted at the Annual Meeting of the Region, shall be forwarded to the National Executive Committee with the Annual Report of the affairs of the Region and any remits or suggestions sought by the Regional Executive Committee to be placed before the Annual Meeting of the Assembly. The Regional Executive Committee shall, in addition, forward to the National Executive Committee on request any other information, budgets or returns as shall from time to time be authorised or requested by the National Executive Committee.
3. A General Meeting of any Region shall be called by the Regional Executive Committee upon a requisition signed by at least ten members and such meeting shall be called within 21 days. The National Executive Committee may call a General Meeting of the members in any Region upon giving the Regional Executive Committee notice of its desire that such meeting be called. If a Regional Executive Committee fails to call such a General Meeting within 21 days then the National Executive Committee may call such a meeting by giving notice to all members in the Region.

## **12. ELIGIBILITY OF NATIONAL EXECUTIVE AND REGIONAL EXECUTIVE COMMITTEE MEMBERS**

1. No employee of the Assembly shall be eligible for election to the National Executive Committee or to any Regional Executive Committee.
2. Only financial Individual or Family Members or representatives of financial Corporate Members shall be eligible for election to a Regional Executive Committee.
3. Any member of the National Executive Committee or any Regional Executive Committee shall be disqualified from office and the membership vacated if the member:
  1. Ceases, for any reason, to be a financial Individual Member or representative of a financial Corporate Member;
  2. Resigns his office by notice in writing to the National Executive Committee or the Regional Executive Committee;
  3. Is removed from office by resolution of the National Executive Committee or, in the case of a Regional Executive Committee, by resolution passed at a General Meeting of the Region convened for the purpose of which due notice of intention to remove from office has been given;
  4. Absents himself from three consecutive committee meetings unless leave of absence has been obtained.

Any member disqualified from office pursuant to sub-clause (iii) shall not, thereafter, be eligible for election to office as a member of any of the said committees without prior consent of the National Executive Committee. Any member disqualified from office, pursuant to subclauses (i), (ii) and (iv) shall remain eligible for election to any of the said committees.

## **13. FUNDS, PROPERTY AND SUBSCRIPTIONS**

1. The funds, income and property of the Assembly from whatever source derived, shall be applied solely towards the promotion of the aims, objects and work of the Assembly.
2. All funds, assets and property received or held by any Regional Executive Committee of the Assembly shall be the property of the Assembly and no Regional Executive Committee shall exercise borrowing or other powers in respect of funds or property without the consent and within the limits from time to time authorised by the National Executive Committee.
3. The National Executive Committee shall control and regulate the management of the bank account or accounts of the Assembly and the means by which cheques shall be drawn or endorsed on behalf of the powers of Regional Executive Committees to operate bank accounts and authorise expenditure.

4. The National Executive Committee shall cause proper books of account to be kept recording receipts and expenditure by the Assembly and its assets and liabilities. The financial year of the Assembly shall end on the 30 June each year and the National Executive Committee shall place before the Annual General Meeting of the Assembly, audited financial statements together with a copy of the Auditor's Report.
5. An annual subscription shall be payable by each Corporate, Individual and Family Member and such subscriptions shall be fixed from time to time by the Annual General Meeting of the Assembly.

## **14. COMMON SEAL**

The Assembly shall adopt a Common Seal which shall be in the custody of the National Executive Committee or such person as they shall appoint. The Seal shall not be affixed to any document except in pursuance of a resolution of the National Executive Committee or a General Meeting of the Assembly and shall be affixed in the presence of two members of the National Executive Committee appointed by it for the purpose.

## **15. ALTERATION OF RULES**

1. These Rules may be altered, added to, rescinded or otherwise amended by a resolution passed by three-fourths majority of voting members attending, by their representative or Individual or Family Members present in person or by proxy at a General Meeting of which 30 days notice has been given PROVIDED THAT no alteration, addition, rescission or other amendment to these rules shall be made which is inconsistent with the charitable nature of the Assembly.
2. Every such notice shall set forth the purport of the proposed alteration, addition, rescission or other amendment.
3. Duplicate copies of every such alteration, addition, rescission or amendment shall forthwith be delivered to the Registrar in accordance with the requirements of the Act.

## **16. DISSOLUTION**

The Assembly may be wound up or dissolved in any of the ways provided in the Incorporated Societies Act 1908. In the event of a winding up or a dissolution of the Assembly, and Extraordinary General Meeting of the Assembly shall be called.

The Assembly shall then proceed forthwith to decide how the surplus assets shall be disposed of and in so doing, ensure that the surplus assets will be applied exclusively for charitable purposes within New Zealand which purposes shall as near as possible resemble the objects of the Assembly. A resolution under this rule as to the disposal of surplus assets must be passed by a majority of two thirds of voting members attending, by their representatives or Individual or Family Members present in person or by proxy. In the event of the Extraordinary General Meeting being unable to pass a resolution required by the provisions of this rule, the provisions of Section 27 of the Incorporated Societies Act shall apply.

## **17. REGISTERED OFFICE**

1. The registered office of the Assembly shall be situated at Level 5, Central House, 26 Brandon Street, Wellington City, or at such other place for the time being as shall be decided by the National Executive Committee.
2. Notice of every change of situation of the registered office shall be duly sent to the Registrar.

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