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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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Finally, thank you to my family for your encouragement and the patient inquiries on the progress of my thesis. A common question in the final six months was “Is that thesis finished yet?” Yes, this thesis is finished, but it has triggered ideas for further projects!

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.