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**From the New Zealand Crippled Children Society to
CCS Disability Action:
A social and political history of a disability organisation in Aotearoa
New Zealand moving from charity to social action**

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

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Mathilde Theresia Maria Schorer

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Abstract

The New Zealand Crippled Children Society, founded in 1935, has emerged as CCS Disability Action in the first decade of the 21st century. This thesis covers the social history of the organisation from 1935 to 1945 and 1997 to 2008, placing it into the societal context of Aotearoa New Zealand by exploring previous histories, examining historical documents and collecting information in interviews with key players.

Analysis of the documentary and interview data is guided by questions about the influence on CCSDA by:

- The changing perception and language around impairment and disability in the last 75 years and the influence of the social model of disability
- The bicultural perspective crucial to social history in Aotearoa New Zealand expanding to multicultural considerations
- The emergence of the disability rights movement and the importance of the UN Convention on the Rights of Persons with Disabilities
- Key developments in social policy in Aotearoa New Zealand and the relationship of non profit organisations and the State with the cross-pollination of innovative ideas and the varying balance of power

Recommendations for CCSDA suggest continuing as a champion for the rights of disabled children and keeping the combination of quality service and social change agenda. A comprehensive history of CCS Disability Action is recommended as an acknowledgment of disabled people's contribution to CCSDA and to society in Aotearoa New Zealand.

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List of Abbreviations

ABCNZ	Association of Blind Citizens of New Zealand
ACC	Accident Compensation Corporation
ADA	Americans with Disabilities Act (1990)
AGM	Annual General Meeting
CEO	Chief Executive Officer
CCS	Acronym for Crippled Children Society
CCSDA	CCS Disability Action, name of the organisation since 2007
DANZ	Deaf Aotearoa New Zealand
DPA	Disabled Persons Assembly
DPEP	Disabled Persons Employment Promotion
DPCW	Disabled Persons' Community Welfare Act
DRM	Disability Rights Movement
IHCPA	Intellectually Handicapped Children's Parents Association
IYDP	International Year of Disabled Persons
LAC	Local Area Coordination (model)
LAC	Local Advisory Committee
LEC	Local Executive Committee

MP	Member of Parliament
NASC	Needs Assessment and Service Coordination
NGO	Non-governmental Organisation
NZCCS	New Zealand CCS, name of the organisation from 1989 to 2007
NZDS	New Zealand Disability Strategy (2001)
ODI	Office of Disability Issues
RNZFB	Royal New Zealand Foundation of the Blind
PLAN	Planned Lifetime Advocacy Network
SIL	Supported Independent Living
SRV	Social Role Valorisation
ToW	Treaty of Waitangi
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities (2006)
UPIAS	Union of the Physically Impaired Against Segregation

Preface

This thesis examines two eras of the 75 year journey from New Zealand Crippled Children Society to CCS Disability Action. My personal involvement with the New Zealand Crippled Children Society (NZCCS) began after my daughter was born with an impairment in 1985 - it is with my daughter's permission that I write about this personal experience. The first time I heard the name Crippled Children Society was a few hours after my daughter's birth and I was shocked by the impact of the word 'crippled'. In the first year of my daughter's life I felt institutionalised by all the professionals visiting our home including the Field Officer of NZCCS. However the information they provided was very helpful and my involvement in a mothers' group established by NZCCS brought me in contact with other women who were fighting for their disabled children's rights to be treated the same as all other children. We were a fierce group, standing up for disability rights and supporting each other. In 1991, NZCCS was seeking parents to take over their childcare centre in Hastings and I established a Trust together with three other women. The Trust took responsibility for running the early childhood centre and for converting it into a commercial business catering for all children including children with impairments. Involvement in local and national governance of CCS Disability Action (CCSDA) followed and at present I am a member of the National Board, which employs the CEO and leads the strategic thinking of CCSDA.

My interest in doing research started when I became aware of the academic discipline of Disability Studies. I had a degree in Germanistik (German literature and language), History and Social Sciences from Regensburg University in Germany which was assessed as the equivalent of a Masters degree in New Zealand. When my two children were settled at school, I followed my interest in Maori Studies and Women's Studies at Massey University extramurally and I expected to continue my academic path in these disciplines. Then my daughter had a severe accident at Riding for the

Disabled at the age of 14. Peoples' reaction to accidental injury compared to congenital impairment was so markedly different, it left me looking for answers regarding this discriminatory behaviour and the reality of a hierarchy of impairments. The Disability Studies papers at Massey offered new insights including the chance of theorising disability, exploring the different models and theories of disability and provided more links to the disability community in Aotearoa New Zealand and in Germany. On a visit to Germany I researched the German Disability Rights Movement and the new discipline of Disability Studies at universities in Cologne and Bremen. This research topic developed after completion of a Postgraduate Diploma majoring in Disability Studies, which included papers on Social Policy and on Research Methods.

The social and political history of CCSDA provides a great platform to examine perceptions of impairment and disability, follow the development of the disability rights movement in Aotearoa New Zealand and explore the influence of government policy on CCSDA. The last history of CCSDA was published in 1995 and it seemed a good time to revisit the first 60 years, add the next 15 years and offer contemporary analysis. The preservation of historic voices and the recording of disabled leaders' voices - recently involved in CCSDA, but since moved on - was another motivation. Right at the start of the research project the decision was made to concentrate on the first decade and the last 11 years of CCSDA's history as the entire history was too big for this thesis. However the fundamental changes in government policy regarding non profit organisations and the rise of the contract culture in the late 1980s and 1990s made it necessary to cover this period briefly and to offer a background for the changes in the external and internal environment of CCSDA.

Chapter One: A social and political history of a disability organisation in Aotearoa New Zealand moving from charity to social action

“We need to move beyond simply judging the past, to understanding it” (Dalley & Tennant, 2004, p. 7)

The research process and outline of chapters

This chapter introduces the research topic and the research process; it covers questions such as why and how the research was conducted and what results might be expected followed by a brief outline of the chapters.

In this thesis the following terms will be used consistently. During the 75 year history three name changes have occurred, from New Zealand Crippled Children Society 1935 to 1989, New Zealand CCS 1989 to 2007 to CCS Disability Action (CCSDA) since 2007. In this thesis, especially in verbatim quotes, the relevant name used at the historical time will appear; in the analysis and conclusion chapters I will use CCSDA as the name for the organisation.

It was a conscious decision to use the full name Aotearoa New Zealand in the title and I will use Aotearoa New Zealand throughout the text.

Discussions about the use of the phrase ‘disabled people’ versus ‘people with disabilities’ have occupied too much time in the past. In this thesis both versions will be used acknowledging: ‘disabled people’ is a political statement about the disabling society and the refusal to be ashamed to belong to the disability community and ‘people with disabilities’ emphasises that people come first, disability second. The influence of the Disability Rights Movement (DRM) is an important aspect of this thesis and the abbreviation will be used throughout.

Research topic and purpose of research

This thesis traces the social and political history of CCS Disability Action (CCSDA) in Aotearoa New Zealand from the vision of the founders to strategic priorities today. This research poses the questions to what extent is CCSDA influenced by:

- The popular understanding of impairment and disability
- The bicultural composition of society in Aotearoa New Zealand
- The disability rights movement
- Government policy

Emphasis is placed on the decade between 1935 and 1945 and on the years 1997 to 2008 with brief excursions into the intervening years to deepen the understanding about important policy developments during the period. The key focus area is whether CCSDA progressed from an all white, middle class, male, and able bodied to a bicultural and multicultural, fully inclusive organisation with leadership by disabled people. The social and political history of CCSDA is investigated by document analysis and by conducting interviews with key people in the organisation.

The purpose of the research is to examine the social and political history of CCSDA in relation to societal reaction to and the treatment of disabled people in Aotearoa New Zealand. The intention is to trace the birth and progress of inclusive practice in New Zealand society regarding its disabled citizens and ultimately the research anticipates contributing to the improvement of disabled people's lives by questioning the advocacy role of social service providers and recommending a disability rights perspective.

Non profit organisations in Aotearoa New Zealand have to acknowledge the bicultural foundation of society because the Treaty of Waitangi is the country's foundation document. Maori involvement dates back to the early years of CCSDA, but Maori concepts of disability such as a holistic concept

with the four cornerstones of Maori health: Te Whare Tapa Wha (Durie, 1994) were not recognised in New Zealand society or by early leaders of the New Zealand Crippled Children Society. Maori families were not prepared to relinquish their children to institutional care for rehabilitation in a Pakeha setting away from the protection of their own culture (Tennant, 2007).

Emphasis is placed on the change of awareness inside the disability community, the influence of the DRM and the dictum ‘Nothing about us without us’ (Charlton, 1998) on CCSDA. The growth of self-advocacy organisations of disabled people such as People First NZ¹ described by Vaccarino (2010) as “the self-advocacy movement within IHC” and the Disabled Persons Assembly (DPA) from its foundation in 1983 (Georgeson, 2000) reflects a unique Aotearoa New Zealand perspective of the DRM.

The influence of non governmental organisations on policy development in Aotearoa New Zealand is of significance as highlighted by Tennant, O’Brien and Sanders (2008) who identify “non profit organisations as another major contributor to social wellbeing beyond the state” (Tennant, O’Brien & Sanders, 2008, p. 35). The relationship between government and non profit organisations can be regarded as complementary, supplementary or adversarial with the adversarial scenario often arising from advocacy for a client group and a desire to influence policy (Tennant, 2007).

Social values are reflected through language and the evolution of the organisation’s name over the last 75 years is an interesting example. Founded in 1935 as the New Zealand Crippled Children Society, the name reflects the charity approach to disability using the medical model paradigm as its basis and placing rehabilitation at the centre. In 1989 the Society changed its name to New Zealand CCS Inc to avoid the word ‘crippled’ now regarded as derogatory and to signal the widening of its client base to all disabled people, not only children with physical impairments. Since 2007 the organisation has been known as CCS Disability Action. Including all

¹ Registered by J.B. Munro in 1984 under the Companies Act (Millen,1999, p. 95).

people and the foundation statement Te Hunga Haua Mauri mo nga Tangata Katoa acknowledges the special connection with Maori as the Tangata Whenua and highlights that all people have Mauri, a unique life force. The question whether CCS Disability Action followed a bicultural path and how successfully the organisation embraced the Treaty of Waitangi as a strategic document is examined by analysis of historical and contemporary documents and in interviews with Pakeha and Maori involved in the organisation.

The significance of the proposed research lies in the establishment of a clear philosophical connection between the discourse of various models and theories of disability and the socio-historical path of CCSDA. The influence of the DRM, the recognition of the Treaty of Waitangi as a foundation document, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) as well as the correlation between public policy and vision statements of CCSDA are significant links to be explored.

This thesis will endeavour to answer the question to what extent governmental social policy and CCSDA's strategic thinking have cross pollinated each other and if needs and rights based policy approaches exerted major influence. The connection between the vision of CCSDA and the social policy direction of successive governments, strong direct influence on social policy and legislation in Aotearoa New Zealand and international Human Rights legislation can be detected in some periods of CCSDA's history.

Documentary data and oral histories

The development of the New Zealand Crippled Children Society from 1935 to 1945 and of NZCCS and CCS Disability Action from 1997 to 2008 will be followed by examining documents such as Annual Reports (1935 to 1945 and 1997 to 2008); Rules of the Crippled Children Society from the 1940's; Strategic Directions and Policies of CCS Disability Action, 2009 - 2014;

and submissions to government on policies and human rights legislation. Early Rotary papers, tracing the time leading up to and exploring the motivation behind the foundation of the New Zealand Crippled Children Society, are examined.

The intervening years between 1946 and 1997 are covered briefly to provide the background and the link between the two eras. Selected minutes of meetings of the National Executive and the National Board respectively provided further information about the motivation, goals and strategic development of CCSDA guided by the different generations of leaders.

The recording of historic voices was important to contribute to the oral history of Aotearoa New Zealand and interviews with three members of the founders' generation add interesting insights. Lady Gillies, the second spouse of the New Zealand Crippled Children Society's founder Sir Alexander Gillies agreed to a recorded interview in Wellington. Tom and Marie Johnson, two early treasurers of the Hawke's Bay branch spoke to me in Napier. The involvement of three prominent leaders of the disability community who have recently been involved with CCSDA - Ruth Jones as Maori Policy Manager, Paul Gibson as Policy Manager and Maurice Priestley, who has been a member of the National Board and is now chair of a local governance committee - add critical analysis to the exploration of recent history. The former CEO, Viv Maidaborn² with her long involvement in the non profit sector has a valuable contribution to make regarding the management structure and CCSDA's services.

The four themes which will be prominent are:

- Disability and impairment responses in society in the 1930s and 1940s and in the late 1990s and 2000s including changing language and discourse
- Bicultural composition of society in Aotearoa New Zealand

² CEO of CCSDA from 2004 to 2011.

- The influence of the New Zealand disability rights movement
- The correlation between government policy and CCSDA's strategic thinking and the relationship between non profit organisations and the State

Outline of chapters

This thesis consists of eight chapters and starts with the presentation of the research topic detailing the topic and the purpose of the research. Chapter One concludes with the following brief outline of chapters.

Chapter Two introduces social history as the methodology of the thesis and is followed by a brief look at published histories of CCSDA. The qualitative method used in data collection and analysis and the researcher's position are presented. Relevant ethical issues are discussed and interview participants are introduced.

Chapter Three: Thinking about Disability starts by looking at the development of the social model of disability as the crucial element of the disability discourse. The popular understanding of impairment and disability and Maori concepts of health and disability are examined. Eugenics, an important influence on societal thinking in the early 20th century, and the new developments in the field of Genetics are covered briefly. Theories of disability such as Normalisation and Social Role Valorisation (SRV) theory and Ableism and Disablism conclude the chapter.

In the first part of Chapter Four key developments in social policy from 1935 to 2008 are covered, starting with the 1935 Labour government's idea of Aotearoa New Zealand as a model welfare state and the 1938 Social Security Act. Policies and legislation in the period from the 1950s to the 1970s are discussed and include reports recommending institutionalisation of disabled people (Aitken Report, 1953), early hints of community care

(Burns Report, 1959) with the establishment of sheltered workshops as a compromise to institutional care (Disabled Persons Employment Provision Act, 1960) and finally the advance of community living in the Disabled Persons Community Welfare (DPCW) Act from 1975. Economic interventionism in the Muldoon years with emphasis on economic policy and the introduction of 'National Super' is followed by the Labour government in 1984 which introduced neoliberal theory but still retained the idea of a safety net for disadvantaged New Zealanders. The New Deal in 1991, with the repeal of the DPCW in the Health and Disability Act of 1993 and changes to ACC legislation towards privatisation in 1998, signalled the devolution of state involvement in welfare provision. The social development approach with its concept of well-being and rights based policy was introduced by the Labour-led coalition government of 1999. This resulted in the repeal of the 1998 Accident Compensation Corporation (ACC) Act in 2000, the New Zealand Disability Strategy (NZDS) in 2001, the repeal of the Disabled Persons Employment Promotion (DPEP) Act in 2007 and led to the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008. These policy development from the mid 1930s to the late 2000s are discussed in the first part of Chapter Four.

The second part of Chapter Four introduces the dictum 'Nothing about us without us' used by the Disability Rights Movement (DRM) worldwide. The development of early self advocacy groups in Aotearoa New Zealand is followed by a look at the pan-disability movement and the foundation of the Disabled Persons Assembly (DPA) in Aotearoa New Zealand in 1983.

Chapter Five uses documentary data to follow the history of CCSDA. The archival material from 1935 to 1945 and 1997 to 2008 includes Annual Reports, selected minutes and policy documents. The beginnings of the New Zealand Crippled Children Society from 1935 to 1945 are closely linked to Rotary clubs, wealthy philanthropists and politicians and Rotary papers as well as speech notes by government ministers are used as primary sources.

The intervening years between 1946 and 1997 are covered briefly providing continuity; emphasis is placed on the extension of the client base and services in the 1950s until 1981. Service development and the rise of the contract culture from 1981 to 1997 are covered next. The Millennium Charter of 1997 and a change of name and strategy in the mid to late 2000s signalled close cooperation with disabled people's organisations and involvement of skilled disabled people in policy development within CCSDA. The chapter concludes with a look at campaigns and new initiatives from 1999 to 2008.

Chapter Six presents the oral histories represented by interviews with key players. The interviews were conducted with three participants who were involved with the New Zealand Crippled Children Society in 1950s and the 1970s respectively and four participants connected with CCSDA in the 2000s. The interviews represent opinions of individuals and all direct quotes from the audio recorded conversations have been approved by the participants. The interview data are presented in the order of the questions asked in the interviews.

Chapter Seven, the analysis chapter returns to the four main elements of influence on CCSDA:

- The perception of impairment and disability in society taking the importance of language into account
- Bicultural composition of society in Aotearoa New Zealand
- The emerging disability community and the Disability Rights Movement
- The relationship between non profit organisations and the State and the cross-pollination of government policy and CCSDA vision in the 1930s and 1940s and from 1997 to 2008

Chapter Eight offers concluding thoughts and starts with a comparison of histories of CCSDA followed by observations and recommendations.

Chapter Two: Methodology and research design

The purpose of this chapter is to place the research in the context of the chosen methodology and to identify the methods used for data collection and analysis. Published histories of CCSDA are introduced and anchored in the environment of the time of their publication. Relevant literature on social history and text books on research methods are addressed in the chapter. The researcher's position is explained and ethical issues are discussed taking both the researcher and the researched into account. The interview participants are introduced at the end at the end of this chapter.

Social history

The social history approach is used to examine two eras within the 75 year history of CCSDA relating to societal development over that time span in Aotearoa New Zealand. Tilly (1985) describes the task of social history as “documenting large structural changes, reconstructing the experiences of ordinary people in the course of those changes, and connecting the two” (Tilly, 1985, p. 31). Tilly (1981) defines social history in his book *As Sociology Meets History* as:

The study of connections between large structural changes and alterations in the character of routine social life. Social history in this sense is the prime region of convergence between sociology and history. In the perspective of knowledge as a whole, social history has two fundamental callings. They are complementary. The first is retrospective: It takes certain features of our contemporary world as problematic and then moves back to trace the origins and transformations of these features ... Social history's prospective calling, in contrast, consists of asking what could have happened to routine social life at major historical choice points, then considering

how and why the outcomes that actually occurred won out over other possibilities. (Tilly, 1981, p. 212)

Hall's (1999) approach to socio-historical research follows Max Weber who in response to the 'Methodenstreit' (fight about methods) at the end of the 19th century declared that "perspectivity is a condition of knowledge" (Hall, 1999, p. 233). Hall extends the binary distinction between modernism and postmodernism to a Third Path to knowledge:

This route depends on understanding inquiry as the product of meaningful social *discourse* ... Understanding inquiry as discourse makes it possible to explore the shared cultural worlds of rhetoric and reason, epistemology and ideology, knowledge and its purposes. (Hall, 1999, p. 16)

This research will use Tilly's (1981) retrospective and prospective elements of social history and his interpretation of social history as convergence between history and sociology. The connection between large structures (Lloyd, 1986), the development of modern societies (Habermas, 1985) and individual people's experience (Weber, 1949; Trevelyan, 1942), all perspectives of social history, will form the foundation of the analytical approach in this research.

Many different aspects are considered from the perception of disability and impairment in society, to different theories and models of disability and Maori concepts of disability (Tenare, 2005; Kingi & Bray, 2000; Durie, 1994); from the influence of the Disability Rights Movement (DRM) in Aotearoa New Zealand to relationships between the non profit and the state sector. Social policy development including specific disability policies such as the New Zealand Disability Strategy (NZDS, 2001) and the growth of the legal framework around disability rights such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) are considered.

Literature investigating the methodology of social history and its problems (Hall 2007, 1999; Lloyd, 1986; Tilly, 1981; Trevelyan, 1942) spans many years. Different elements of social history practice will be involved such as the research into peoples' lives through interviews supported by Trevelyan's (1942) view that social history examines the experiences of ordinary people. The investigation of macro structures, as advocated by Lloyd (1986), is envisaged by placing the social history of CCS Disability Action in its societal context.

In the data analysis chapter the social history approach uses elements of the transformative research paradigm to reflect the voice of disabled people and to partner with disabled people to achieve social change towards inclusion.

Published histories of CCSDA

Following the socio-historical content of this research previous histories of the organisation play an important role and the three previous histories of the organisation are examined. The first, written by Carey in 1960 covers the first 25 years of the New Zealand Crippled Children Society followed by an internally circulated, typed manuscript from 1984 presenting history from 1935 to 1984 and a pictorial history published in 1995 for the 60th anniversary of the renamed New Zealand CCS. Neither the 1984 and 1995 historical records specify an author, but both mention the New Zealand Crippled Children Society as the publisher.

Carey (1960) presents the history of the New Zealand Crippled Children Society with one chapter per year, a chronological account of meetings between medical professionals, Rotarians and rich benefactors of the founder generation. Emphasis is placed on monies donated, professionals and 'crippled children' sent overseas with the society's funding to explore rehabilitation methods and to receive ground breaking surgical treatment respectively. The views of disabled people are not taken into account in the first history by Carey (1960).

The typed manuscript of the second history (1984), unpaginated and with the authorship unacknowledged, describes disabled people as “those unfortunate enough to be disabled” (New Zealand Crippled Children Society History, 1984, unpaginated). Improvements of services and achievements in the International Year of Disabled Persons in 1981 are credited to professional administrators and office holders in the organisation. The 1984 history is written from a national office perspective and often reads like a document justifying and defending the existence of the national office, highlighting the importance of the national office to the work done in the branches. There is no acknowledgment of any involvement of disabled people in the New Zealand Crippled Children Society but there are hints of conflict with the emergence of Disability Rights groups and the establishment of the DPA in 1983.

The third, pictorial, history (1995) published by NZCCS National Office (Project Coordinator Michelle Hill) offers a different perspective and highlights achievements of disabled people. The Treaty of Waitangi is officially recognised by the organisation and a new name signals a change in direction, which is accentuated by the establishment of a consumer advisory group in 1989. The pictorial history of NZCCS from 1995 hints at the importance of independence, advocacy and biculturalism, but does not offer a clear philosophical foundation for the changed strategic direction, which welcomes the involvement of disabled people.

Other complementary sources of information about CCS Disability Action are provided by documents such as Annual Reports, minutes and strategic direction papers and interviews. All data used in the research are analysed using qualitative methods as detailed below.

Methods: Data collection and analysis

All data collection, interviews and document analysis in this research uses qualitative methods. The New Zealand Crippled Children Society had its

beginnings in Wellington and the library with the original documents is located there. Access to primary sources used in this research for document analysis was authorised by the CCS Disability Action Board. The annual reports from the first decade 1935 to 1945 and from 1997 to 2008 are complemented by documents such as *Rules of the Society* (1940), the *Millennium Charter* (1997) and the newest strategic document *Strategic Priorities 2009 to 2014* (2009).

Seale (2004) did not regard documents and archived texts as evidence in the realist approach, but as resources using the social constructionist approach and he introduced authenticity, credibility, representativeness and meaning as four criteria for judging archived documents. Furthermore archived documents have to be examined regarding: their genre conventions, actual material production and their intertextuality, interpreting “intertextuality in two key ways: there are relationships of sequence and relationships of hierarchy” (Seale, 2004, p. 257). The production of archives presented further complications in this research and questions about serialisation and fragmentation of files have to be asked including what is missing, who produced the archives and what was the social context in which these documents were produced?

Documents by themselves were not regarded as sufficient data for the research project. Interviews with participants involved with the New Zealand Crippled Children Society and with people in important roles in the last decade of CCSDA were seen as crucial for supplementing the information about the organisation and the societal background of the respective periods.

Interviews were conducted using the semi-structured technique. The combination of predetermined questions and free flow conversation presented the most appropriate way of data collection in this context and provided the opportunity for the researched to have input in the interviewing

process. O’Leary (2004) defined interviewing as “a method of data collection that involves researchers asking respondents basically open-ended questions” (O’Leary, 2004, p. 162).

O’Leary (2004) highlighted the complexity of interviewing and divided it into the complexity of people and complexities of communication. The research questions were developed together with disabled people working in the organisation and are designed to reach people and to aid understanding. The interview questions are linked to the research questions; questions about societal treatment of disabled people and the bicultural perspective are directly linked. The connection to the DRM, corresponding policy development and the relationship between non profit organisations and the State are covered in the personal and general questions.

Interviews of members of the founders’ generation, management and governance members of the organisation and disabled and non-disabled leaders of the organisation today, were conducted in an informal way but sometimes in formal settings like an office or the boardroom of CCSDA. All interviews have been audio recorded with the permission of the interviewees. Appendix One includes the information sheet, Appendix Two the consent form and Appendix Three the interview schedule which were sent to all participants (pp.187-192).

O’Leary (2004) presented the process of reflective analysis putting data analysis at the centre of the research process and demanded the observation of the overall aims and objectives of the research project as well as the collection and interpretation of data to ultimately draw conclusions without forgetting methodological boundaries and theoretical background. This research will use the qualitative data analysis strategy of thematic analysis identifying themes that have evolved as the research unfolds. One of the challenges of conducting research is trying to abstain from forcing data into certain themes and managing subjectivities; these will be addressed next.

Researcher's position

The acknowledgment of the researcher's own reality and of the influence of the individual socialisation on research is crucial. "We are all products of the social forces that surround us. We carry with us the biases and prejudices of both our attributes and our socialisation" (O'Leary, 2004, p. 43).

Researchers must be aware of bringing in their values and as O'Leary (2004) writes "that they recognise and manage ... value and use subjectivities endemic to the research process" (O'Leary, 2004, p. 7).

Recognising and managing subjectivities is particularly important as my position has elements of being an insider and an outsider. I qualify as an insider as a parent with a vicarious experience of disability, as a CCS Disability Board member and as a researcher in the field of Disability Studies.

However, some members of the disability community only accept researchers with an impairment as insiders following the dictum 'Nothing about us without us'. As a European immigrant experiencing the cultural differences in society and in the academic world of my country of origin Germany and Aotearoa New Zealand, puts me in the category of an outsider. The lack of experience with indigenous populations and with the historical grievances resulting from colonial injustices of previous generations might create problems with understanding political realities in Aotearoa New Zealand.

Fay (1996) accepts both insider and outsider researchers and states that it all depends on "the requisite openness, sensitivity and acuity to grasp the significance of activities, experiences and their expression" (Fay, 1996, p. 26). The transformative paradigm used insider epistemology to highlight the interactive link between the researcher and the researched: "knowledge is socially and historically located within a complex cultural context" (Mertens, 2007, p. 216).

Awareness of the historical context highlighted another problem, that was the long time span covered. Many members of the founder generation have passed away and the archived documents had to be viewed critically for accuracy and placed into their socio-historical context. Critical awareness of the interviewees from the founders' generation about strategic priorities of the organisation and theories and models of disability were of their time. The social context during the time of the individuals' involvement in the organisation has to be exposed and critically assessed.

Other problems have emerged during the analysis of data and have been managed by adherence to the chosen methodology and by ensuring that the relationship with the research participants was handled with integrity and honesty and according to ethical guidelines.

Ethical issues

Ethical considerations are high on the list of priorities when qualitative research methods are used. Ethical considerations regarding a possible conflict of interest - the researcher is a member of the CCSDA Board - made a request to the CCSDA Board for research approval necessary and no conflict of interest was detected. The research project has the ethical approval of the Massey University Ethics Committee (Massey University Human Ethics Committee: Southern B, Application 10/31).

The intention of the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participation (2009) is:

To provide protection for all participants in research ... as well as to protect researchers and institutions. The Code is an expression of the basic human rights of respect for persons, autonomy, privacy and justice. (Massey University Code of Ethical Conduct, 2009)

Principles of ethical conduct include informed consent, privacy, confidentiality, respect for people as well as social and cultural sensitivity. O'Leary (2004) divided the ethical responsibilities into responsibility for the production of knowledge and responsibility for the researched. Fulfilling the responsibility for knowledge production required the researcher to acknowledge subjectivities, report accurately and stay within the law. Knowledge of previous relevant research literature and previous experience is expected. The responsibility for the researched included demands like cultural awareness and sensitivity towards social circumstances, informed consent, confidentiality agreements as well as accurate risk assessment particularly when interpreting personal information obtained in interviews.

Kvale (1996) described stages of qualitative research interviewing and the ethical issues connected to them. During the design stage questions of consequences for the interviewees, informed consent and confidentiality emerge. The interview situation itself might confront participants with stress and a change of self-image and the transcription demands accuracy in the translation from oral to written form. Thematising the interviews involved thinking about the scientific value of the research combined with the improvement of the human condition. Interview analysis has to involve participants in the interpretations of their statements so that the verification reported the acquired knowledge as confirmed and secure. Reporting finally highlighted the opportunities for the individuals or the group they represented and emphasised confidentiality again.

Kirkman (2001) in her *Ethics and the Politics of Research* highlights the problem of abuse of the researched group by outsiders such as feminist and homosexual research and touched on the problematic of insider and outsider epistemology. Similarly, some disability activists promoted the notion that research about disability issues should be conducted exclusively by disabled people (Charlton, 1998). Strict adherence to ethical research guidelines prevents abuse even if the researcher does not have a lived experience of

disability and ethically conducted research about disability issues was welcomed by disability rights advocates who appreciate ‘allies in emancipation’ (O’Brien & Sullivan, 2005).

Adherence to the three principles of respect, beneficence and justice will add to the ethical safety of this research project. Having consideration for cultural norms, promoting human rights as well as increasing and advancing social justice are principles stressed by the transformative research paradigm (Mertens & Ginsberg, 2008, a). Research has to be ethical but also vigorous and has to adhere to the five categories of ethical qualitative research: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (Lincoln, 2008). Fairness is important for the research design because many protagonists have passed away and their contribution has to be placed within the historical context of the society they lived in.

Disability research is closely linked to the social model of disability and aimed at the improvement of the lives of disabled people. “The social model of disability provides the ontological and epistemological basis for ethical disability research” (Sullivan, 2008, p. 81). Respect for research participants demanded a free choice of preferred language. Sign language was not relevant for any of the interviewees. Maori words and phrases were used in some interviews. Some were translated into English, others are used in everyday language in Aotearoa New Zealand and did not require translation.

Access to results of the research is a basic right of participants, questions of ownership of data and conclusions, the benefits for research participants, reciprocity and avoidance of harm and conflict of interest are just some ethical considerations (Punch, 2006). The respect for the researched was of particular importance, including the issues of informed consent, the principle of no harm and confidentiality. Being aware of the subjectivities such as the insider and outsider status, the importance of acknowledging the

influence of world views and the obligation of acting ethically were crucial elements of the research process.

At the end of this chapter, the interview participants are introduced establishing their time of involvement and their position in CCSDA.

Introducing the research participants

The interviews with the seven participants were conducted in Wellington, Hawke's Bay and Christchurch. Three participants, who were involved with the New Zealand Crippled Children Society in the 1950s and 1970s respectively, present an important connection with the early history of the Society. The four participants representing the last 11 years of CCSDA clarify trends in the strategic thinking of recent years.

Lady Gillies has a long association with the national society as an Honorary Vice President from 1982 to 2007 and from then as an Honorary Member.³ She is the patron of CCS Disability Action's Wellington branch since 1987.

Marie and Tom Johnson⁴ were active as secretary/treasurers of the Hawke's Bay branch of the New Zealand Crippled Children Society from the late 1950s until the 1970s. Tom and Marie Johnson's contribution is interesting because they answer the questions from a local branch rather than a national perspective.

Ruth Jones, a former Tumu Whakarae, the Maori Policy Manager at National Office in Wellington from 2006 to 2010, a professional in the social work field and user of NZCCS services as a child spoke to me at her home in Christchurch.

³ The position of Honorary Vice President was disestablished in 2007 and changed to Honorary Member.

⁴ Marie Johnson told me the very sad news of Tom Johnson's death in September 2011 when I talked to her in October to confirm the interview data.

Paul Gibson, CCSDA's Policy Manager and leader of the policy team at National Office (part-time from 2002, full-time from 2006 until 2009) and former DPA president (1997 to 2000) agreed to an interview in Wellington.⁵

Maurice Priestley, who used the services of the New Zealand Crippled Children Society as a child and has vast experience in the national and local governance of CCSDA, talked to me at his home in Wellington.

Viv Maidaborn, CEO at the time of the interview at CCSDA's National Office in Wellington in 2010, offered her knowledge about the services and strategic priorities of CCSDA.

Four participants became involved with the New Zealand Crippled Children Society and NZCCS as adults including one participant who established a connection as a student driven by his work as Student Association president, lobbying for supplementary funding for students with disabilities. Two interviewees were involved with the New Zealand Crippled Children Society as children using the organisation's services and one participant encountered the Society as a child because her mother was employed at the Wilson Home. Two of the participants are Maori, five are Pakeha and three of the interviewees identify as disabled people. Interview participants are introduced in Figure 1 below, stating their time of involvement, their position and if they are of Maori decent and identify as a disabled person.

⁵ Paul Gibson was appointed as the Human Rights Commissioner with responsibility for disability issues in September 2011.

Participants	Lady Gillies	T. and M. Johnson	Ruth Jones	Paul Gibson	Maurice Priestley	Viv Maidaborn
When	1970s-now	1950s-1970s	1969; 2000s	1990s; 2000s	1950s; 1980s; now	1970s;1980s; 2000s
Maori			yes		yes	
Position	Patron	Treasurer	Client as a child; Social worker	Contract Policy manager	Client as a child; Board; LAC	Family involvement; Manager Wilson Home; former CEO
Identifies as a disabled person			yes	yes	yes	

Figure 1: Interview participants

The introduction of interview participants personal connection to CCSDA concludes the methodology and research design chapter and the next chapter introduces the social model of disability as the cornerstone of the thinking around disability, looks at the popular understanding of impairment and disability and Maori concepts of health and disability. The excursion to Eugenics and Genetics provides a background to the thinking around disability now and in the past. A brief enquiry into theories of disability such as Social Role Valorisation and Abelism and Disablism concludes Chapter Three.

Chapter Three: Thinking about disability

In this chapter various ideas around the thinking about disability will be addressed starting with the social model of disability (Oliver 1996, 1990; Zola, 1994; UPIAS, 1976), the foundation of the thinking around disability in the late 20th century and the first decade of the 21st century. The popular understanding of impairment and disability including distinctly Aotearoa New Zealand Maori concepts of health and disability are followed by a brief glance at Eugenics with its influence on popular thinking in Aotearoa New Zealand at the beginning of the 20th century and at Genetics which is becoming more prominent in recent times. Theories of disability (Barnes & Mercer, 2010, 2004; Campbell et al, 2008; Davis, 2006) such as Normalisation theory, Social Role Valorisation (DePoy & Gibson, 2011; O'Brien & Sullivan, 2005; Thomas & Wolfensberger, 1999; O'Brien & Murray, 1997) and Ableism and Disablism (Campbell 2008, 2001; Rosenwasser, 2000; Linton, 1998; Hahn, 1986) are presented at the conclusion of this chapter.

Development of the social model of disability

A big change in the thinking around disability occurred when disabled critics and analysts started theorising disability and developed new models of disability in Britain and the United States (Zola, 1994; Oliver, 1990; Finkelstein, 1980; Union of the Physically Impaired Against Segregation (UPIAS), 1976).

The development of new thinking around disability in Great Britain had its foundation in the politicising of disabled people. Sullivan (2008) describes the development of the analysis of disability in the UK:

In the United Kingdom, activists adopted a more explicitly structural analysis of disability in which the distinction between (biological) impairments and (social) disability is far more sharply drawn and

which allowed disability to be recast as social oppression (Shakespeare, 2006). This social model of disability provided the theoretical underpinnings for the first course in disability studies in the United Kingdom in 1975 at The Open University. (Sullivan, 2008, p. 71)

In the United States activists lead the charge. “Within the US, disability studies/ activists have largely followed a minority group model rather than the structural, social oppression model of their UK counterparts” (Sullivan, 2008, p. 72).

At Berkeley, California, physically impaired disability activists founded the first centre for independent living in the US in 1972 (deJong, 1979). These activists adhered to the belief that the barriers they faced to exercising their citizenship were more the product of social attitudes than their individual impairments (Bowe, 1978; Hahn 1985). This social understanding of disability provided the theoretical basis on which the disability rights movement in North America adopted the notion of people with disabilities as belonging to a minority group which was systematically discriminated against in ways which denied members their civil and individual rights. (Sullivan, 2008, p. 71)

Although there were differences in approaching the new thinking around disability in the UK and the USA, both presented the discovery that it was time to fight for disabled people’s rights:

Notwithstanding the differences in perspective, both US and UK disability activists and academics were redefining who they were and proclaiming: “we are not your passive, tragic recipients of care but active, self-determining subjects who demand our rights to be included as free and equal citizens”. (Sullivan, 2008, p. 72)

The definition of disability as socially created and imposed in addition to impairments changed the thinking around disability. Disabled activists cum academics expanded on the innovative thinking and developed the social model of disability.

Towards the end of the 1960s this view began to be challenged first in the area of intellectual disability by normalization theory as developed by non-disabled academics (see Nijre 1969; Wolfensberger 1972) and then by disabled people themselves who in their reconceptualization of disability gave the world the social model of disability (see UPIAS 1976; Oliver 1990). (Sullivan, 2008, pp. 70-71)

In 1976 the British Union of the Physically Impaired Against Segregation (UPIAS) offered the following definition of disability:

Our own position on disability is quite clear ... In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976, pp. 3-4)

The academic discourse exposed the medical and individual model of disability as patronizing and restrictive. Oliver (1996) criticized the medical model of disability and wrote that:

There is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalization is one significant component ... The individual model ... was underpinned by what I called the personal tragedy theory of disability [and] it also included psychological and medical aspects of disability. (Oliver, 1996, p. 31)

The rejection of the medical and individual model and the development of the social model of disability (Oliver, 1997, 1996, 1990; Finkelstein, 1980) had a significant influence on the DRM and on the academic discipline of Disability Studies worldwide. Although many critics suggested an expansion of the social model (Thomas, 2007; Shakespeare, 2006 a; Crow, 1996; French & Finkelstein, 1993) and various expanding and competing models have been developed (Cameron, 2008; Waldschmidt, 2006), the importance of the social model on the disability discourse is undeniable.

The social model and the closely related affirmative and cultural models marked the beginning of a new approach to the thinking about disability. The social model used the theory of social oppression claiming that disability was the result of discrimination and therefore a social problem.

In many countries of the world, disabled people and their allies have organised over the last three decades to challenge the historical oppression and exclusion of disabled people ... Key to these struggles has been the challenge to over-medicalised and individualistic accounts of disability. While the problems of disabled people have been explained historically in terms of divine punishment, karma or moral failing, and post-Enlightenment in term of biological deficit, the disability movement has focused attention onto social oppression, cultural discourse, and environmental barriers. (Shakespeare, 2006 a, p. 197)

The basic solution was social action not individual treatment and experiences of disabled people were used as the foundation. Individual and collective responsibility was necessary to achieve full civil rights which are an entitlement to all. The goal was not individual adjustment but social change. “The affirmative model, building upon the social model, provides a framework for the personal understanding and address of the day-to-day interactions in which we are continuously engaged” (Cameron, 2008, p. 27).

The cultural model of disability (Waldschmidt, 2006) expanded the social model and used the theory of deconstruction treating disability as a result of stigmatising. Disability was seen as a cultural interpretation and the action model leading to solutions was variety. Experiences of all members of a culture were the foundation not just experiences of disabled people. Individual and societal acceptance is only possible if disabled people were not regarded as a minority which has to be integrated, but as an integral part of society (Stiker, 2002). Acceptance of all members of society lead to the goal of cultural change.

The medical and individual models are determined by the rehabilitation paradigm and social, affirmative and cultural models are all constructs of the academic field of Disability Studies. The social model works from the theory of materialism, defines disability as social oppression and uses experiences of disabled people as the foundation. The affirmative model stresses the distinction between impairment and disability and the importance of acknowledging impairment and pain as factors in disabled people's lives. The cultural model comes from the theory of deconstruction, uses a cultural interpretation of (Dis)Ability and utilises experiences of all members of a culture as the base. Social action and self-help are methods employed by the social model, which regards civil rights as an entitlement and has social change as its ultimate goal.

Barnes and Mercer (2010) emphasise that the social model's "impact on current policies across a diverse range of organisations, including central and local governments, charities and voluntary agencies ... highlights the importance of exploring the very contrasting interpretations of the social model" (Barnes & Mercer, 2010, p. 36). There is no doubt that the discourse around the social model had a dominating influence on the thinking around impairment and disability over the last four decades.

Popular understanding of impairment and disability

The language defining disability and disabled people has changed considerably from the 1930s to today: from crippled children, handicapped, mentally retarded and imbecile to persons with disabilities, physically or mentally challenged, learning difficulties, impairments and disabled people. However the distinction between impairment and disability has not entered society's consciousness, but is vital to end discrimination against disabled people and for the promotion of rights for disabled people:

There is a whole dimension of disability ... that is conspicuously absent from our functional deficit definition of impairment. The missing dimension in question is the socio-cultural one. Impairment is a simple, objective, biological phenomenon; disability is a complex social and cultural one ... the distinction is exactly the same as that between 'race' and 'sex' on the one hand, and 'ethnicity' and 'gender' on the other. The former are physical states, the others are social identities. (Beatson, 2000, p. 35)

The negative attitude towards people with disabilities was based on two faulty assumptions according to Asch (2001). First, that any impairment presented tragedy and created a disrupted life and second, that this lead to poverty, isolation and lack of power. The position non-disabled people took towards disabled people was therefore mostly negative with behaviour towards this group in society ranging over time from denial of goods and services, to incarceration, even to elimination as a consequence of eugenic policies in the 20th century (Hubbard as cited in Deal, 2003). Research in this area suggested that a negative attitude existed towards all disabled people uniformly, but certain groups have more difficulty in being accepted thus creating a hierarchy of impairment (Deal, 2003). For example, people with mental health issues and intellectual impairment are more stigmatised than those with physical or sensory impairments. Another interesting aspect was how results change when participants ranked the health conditions by

the degree of social disapproval or stigma and Deal (2003) concluded “wheelchair users, whilst being regarded as facing the most disablement, are also the most socially accepted” (Deal, 2003, p. 900).

Another important element influencing the perception of impairment and disability is language used in society everyday which can form and transform societal thinking (Jaeger & Bowman, 2005; Kendrick & Hartnett, 2005; Dalley & Tennant, 2004). The popular perception of impairment and disability is guided by the language of each historical period; the labelling of disabled people as ‘misfits, degenerates, patients, consumers or clients’ reflected the Zeitgeist and exposed societal thinking at the time.

At various times the state and other agencies have actively promoted a language shift in an attempt to alter or shape popular perceptions ... The connection between history and social policy is marked by language shifts as some terms are promoted and others disappear or go underground on account of an acquired stigma or perceived offensiveness. Attitudes have proven more resilient, sometimes surviving to taint the new terminology, sometimes giving new meanings to words in constant usage. (Dalley & Tennant, 2004, p. 11)

An important shift in language happened with the distinction between impairment and disability and the term ‘disabled people’. Oliver (1996) explains that his “definition of disabled people contains three elements; (i) the presence of an impairment; (ii) the experience of externally imposed restrictions; and (iii) self-identification as a disabled person” (Oliver, 1996, p. 5).

Kendrick & Hartnett (2005) confirm that language determines value and that words can hurt.

It is perhaps unusual to think of human beings as creatures that might be hurt by words ... We may pretend that words do not matter, but

when they are applied to us in a way that diminishes us in front of our peers, the pain is all too real. There is pain in stigmatisation.
(Kendrick & Hartnett, 2005, p. 35)

Ludwig Wittgenstein (1889-1951), an Austrian philosopher and professor of philosophy at Cambridge University, was seen as the initiator of ordinary language philosophy. Wittgenstein's early philosophical thoughts on language in the *Tractatus logico-philosophicus* (1921) are presented by Silby (1998):

Wittgenstein offers us a different way of viewing human thought. For Wittgenstein, all aspects of the human mind are inescapably dependent upon the use of language. A cartesian view would maintain that thoughts and representation are possible without language, but Wittgenstein does not agree ... The crucial point for Wittgenstein is that language is the only way by which we can picture the world ... In the *Tractatus*, Wittgenstein had stated that a name *means* the object that it designates. So, the object being pointed at literally *is* the meaning of its name. (Silby, 1998, unpaginated)

Silby (1998) continues with Wittgenstein's revision of his earlier views in the posthumously published *Philosophical Investigations* (1953):

The importance of language is a view that Wittgenstein stresses through most of his work, although in his later work he challenged his earlier views and decided that language did not mirror reality. It is more likely the case that reality is dependent on our use of language ... For Wittgenstein, it is our language that shapes reality, not the other way around. Only by using a public language can we conceptualize and understand the world around us ... On Wittgenstein's account, language is a crucial part of our ability to conceptualize the world. Language shapes the world. (Silby, 1998, unpaginated)

According to Wittgenstein's interpretation language determines the world's and society's concept of reality. Consequently derogatory and distorting language used for any group in society affects society's view of this group and the treatment the group receives. It can be argued that in the case of disabled people the use of language such as 'suffering, confined to a wheelchair' or similar expressions paint disabled people as the victims and reinforce the individual model view of disability as tragedy. "Language informs attitudes and beliefs because it is a medium of translation of expression and thought. When a word or an idea is expressed, an image is generated" (Charlton, 1998, pp. 65-66).

Attitudes towards impairment and disability can vary considerably in a different cultural context. Aotearoa New Zealand with its bicultural foundations has to acknowledge differences of concepts of health and disability in Pakeha and Maori cultures.

Maori concepts of health and disability

In Aotearoa New Zealand the holistic Maori health concept shapes attitudes towards disability and shows significant difference between the indigenous and the Pakeha culture's approach to disability and responses in the form of disability services:

Mason Durie and others have since contrasted this approach with the more holistic interactions of spiritual (taha wairua), mental (taha hinengaro), physical (taha tinana) and family (taha whanau) dimensions of well-being which informed Maori understandings of health. (Tennant, 2007, p. 102)

According to Kingi and Bray (2000), a Maori concept of disability rests on Te Whare Tapa Wha, the four cornerstones of Maori health (Durie, 1994). "Family, cultural heritage, identity and physical environment are all

described as a set of pre-requisites for health and are primarily external to the individual” (Kingi & Bray, 2000, p. 5).

Tui Tenare (2005) describes Te Roopu Taurima, a service for offenders with intellectual disability using Maori kaupapa and states that “the focus remains on each individual person” (Tenare, 2005, p. 133) She highlights “whanaungatanga (relationship), whangai (foster-care) and rangatiratanga (self-determination)” as the Maori concepts used by this service and describes “whanaungatanga as connectedness of relationship”, “whangai as caring for others as if they were your own” and “rangatiratanga as promoting self-direction” (Tenare, 2005, pp. 129-132).

The holistic viewpoint connects the Maori attitude to health and disability and determines the multi-faceted responses to both. Kingi and Bray (2000) acknowledge that their “research outcome has been the revelation of ‘a’ Maori world view of disability. This cannot be regarded as ‘the’ Maori world view of disability, if in fact such a view exists” (Kingi & Bray, 2000, p. 5). Maori concepts of health and disability have to be acknowledged in Aotearoa New Zealand to honour the bicultural foundation of the society.

Before moving on to theories of disability it is important to have a brief look at Eugenics which influenced societal thinking and policy making in Aotearoa New Zealand in the early 20th century and at Genetics, an emerging field of science.

Eugenics and Genetics

The eugenics movement had its origins in Britain and was closely related to social Darwinism. In 1883 Darwin’s cousin, the British scientist Francis Galton adapted the Greek word eugenes (meaning well-born) to encompass the social uses to which the knowledge of heredity could be put to achieve the goal of ‘better breeding’ (Stepan, 1991). Later, Eugenics became a

movement to improve the human race or to preserve the purity of certain groups (Mazumdar, 1992). The eugenics movement was very influential in Britain spreading to Europe and consequently to Aotearoa New Zealand. Concepts of social selection were used to improve 'racial fitness' in populations. People regarded as 'unfit' and defined as "many kinds of men that we do not want. These include, the criminal, the insane, the imbecile, the feeble in mind, the diseased at birth, the deformed, the deaf, the blind" ([Leonard] Darwin as cited in Sullivan, 1996, p. 92) were subjected to sterilisation or incarceration in the case of people with 'mental deficiencies'.

Metcalf (2000) highlights the split into positive and negative Eugenics. Positive Eugenics functions by promoting and financing the growth of families regarded as healthy and worthy citizens. Negative Eugenics works by limiting reproduction of 'unworthy' citizens and includes sterilisation and euthanasia programmes.

In Aotearoa New Zealand both the negative and positive concepts of Eugenics became influential at the beginning of the 20th century. Chapple promoted negative eugenics and sterilisation of the 'unfit' in the first decade of the 20th century linking physical and mental impairment with an uncontrollable and dangerous urge to reproduce (Sullivan, 1996). The concept of positive, environmental Eugenics and the idea of mothercraft promoted by Plunket's founder Truby King exerted great influence and King was appointed as a member of the Inquiry into Mental Defectives and Sexual Offenders.

The Inquiry into Mental Defectives and Sexual Offenders in Aotearoa New Zealand in 1924 expressed concern at 'feeble-minded' children. Action was needed to prevent 'the multiplication of these degenerates' and infection of 'an inferior strain' in the New Zealand population. The goal was to "increase the elements of the mental, moral, and physical strength of the nation" (Committee Report, 1924). "Eugenics shaped the report of the 1924

Inquiry into Mental Defectives and Sexual Offenders, its very title suggesting an unwholesome coupling of condition and consequence” (Tennant, 2007, p. 102). According to Tennant (1996) “the eugenics movement, influential among politicians and policy makers in the early years of the century [20th century], was less reputable by the 1930s” (Tennant, 1996, p. 22).

With Eugenics discredited, attention shifted to scientific advances in the field of Genetics and the impact on the lives of disabled people. With the advance of scientific research, Genetics has emerged as an important field with its ability to identify individual genes and resulting changes. Scanning for an ‘abnormal’ foetus in the womb is recommended by medical professionals to pregnant women over a certain age or with a history of impairment in the family. In the case of detection of a faulty gene, abortion is strongly advised to spare the unborn child the ‘suffering’. “Disabled people are under threat for their existence in our modern technological societies. Medical science feels able to flex its muscles and power to abolish all life where the unborn foetus may be imperfect or impaired” (Rock, 1996, p. 121). Medical advances in the future signal possibilities of genetic design which could completely erase the congenital appearance of impairment in populations targeting especially Down’s Syndrome and Spina Bifida (Disability Awareness in Action, 1997).

Controversially medical advances were used to ‘design’ two deaf babies in the USA where a lesbian couple, who were both deaf, chose a deaf semen donor and had two deaf babies. Their argument was exactly the same as the one by parents wanting to avoid babies with impairments, they wanted a child after their own image and they wanted to pass on their deaf culture, their language and their lifestyle to their children (Spiewak & Viciano, 2002).

Eugenics and Genetics can be regarded as a quality control tool in societies, regulating the rise of unwanted people and fostering advances for preferred

citizens and their families. Attitudes towards disabled people have been researched by various academic faculties and theories of disability (Barnes & Mercer, 2010) such as Normalisation theory and SRV, Ableism and Disablism have been developed, all of which critique eugenic and genetic approaches to disability.

Theories of disability

Theories of disability use different approaches: the materialist perspective (Finkelstein, 1980) with its extension into the socio-economic approach (Oliver, 1990); the socio-political approach (Zola, 1994) or the approach of identifying disability as social and internalised oppression (Abberley, 1987).

A historical materialist account of disability was presented by Finkelstein (1980). He identifies three distinct stages in the historical treatment of disability, the pre-industrial time, industrial capitalism in 19th century Western Europe and North America and the reintegration of disabled people into post-industrial society with the use of new technology.

Oliver (1990) extends the materialist perspective of disability and adds social factors to the economic influences creating a **socio-economic approach**:

Two factors are central to Oliver's account of the role of ideology in the social creation of disability: first, the individualising tendencies accompanying capitalist development and, most notably, the growth of the free market economics and the spread of wage labour; and, second, the medicalisation of the means of social control - specifically the medical profession's rise to prominence within institutions for sick and disabled people which generated notions of an 'able-bodied individual'. (Barnes & Mercer, 2010, p. 83)

The American version of a **socio-political approach** concentrated on ‘disability’ as an administrative issue arising out of the interaction between impairments and a range of environmental and socio-economic characteristics such as gender, age, and education (Zola, 1994). “It was sustained by continuing civil rights struggles to achieve ‘majority status’ rights and entitlements” (Barnes & Mercer, 2010, p. 77).

Abberley (1987) based his theoretical framework around **disability as social oppression and internalised oppression** which impedes the “political consciousness among disabled people” (Abberley, 1987, p. 6).

A theory of disability as oppression ... is inevitably a political perspective, in that it involves the defence and transformation, both material and ideological, of state health and welfare provision as an essential condition of transforming the lives of the vast majority of disabled people. (Barnes & Mercer, 2010, p. 34)

Munford and Sullivan (1997) remind us that:

The social theory of disability is grounded within the sociological tradition which examines how social institutions, populations and social practices are created, legitimated and maintained. Sociological analysis defines disability and disabled people as being both socially constructed and socially created. They are socially constructed through ideology emanating from the medical paradigm and socially created by the practices which result from that ideology. (Munford & Sullivan, 1997, p. 19)

Barnes and Mercer (2010) described how disabled academics in the United States and the independent living movement on American university campuses developed the first sociological framework. Disability was interpreted as a distributive category within state welfare systems, a highly

political social construction legitimised by medical expertise and formal administrative division.

Another aspect of the sociological examination was the growth in human services industries versus primary production industries. Wolfensberger (1998) theorised that prices for primary products were kept artificially low to reduce the workforce in this sector and to grow the human services sector with the result of creating more dependent and devalued people.

Wolfensberger's normalisation and later social role valorisation principles, suggested solutions to the devaluation of disabled people, but were problematic because they attempted to change disabled people to be more normal and didn't challenge the societal concept of normality. The relationship between disability and the evolution of industrial society exposed the area of disability to business interests. The growth of the rehabilitation industry with the sale of equipment and aids, drugs and private insurance and the expansion of residential facilities commodified disability.

Summary

Theories of oppression exist for many other minorities in society and disability can be identified as a discriminatory marker, together with gender, ethnicity, sexuality, age and social class, and as a reason for being the 'Other'. Identity and difference, disability versus impairment and the renewed discourse around impairment characterise the post-modern approach to disability theory. The dichotomy 'normal abnormal' is being rejected by some postmodern theorists, the critique of the social model and its dichotomy between impairment and disability (Shakespeare, 2006; French & Finkelstein, 1993; Crow, 1996) continues. "The formulation of a politics of resistance can result in the transformation of consciousness and, in the longer term, structural change that will lead to material emancipation of disabled people in Aotearoa New Zealand" (Munford & Sullivan, 1997,

p. 33). Impairment as part of the experience of disability is acknowledged and being seen as the 'Other' has been treated by minority groups as an opportunity to emancipate, exert influence on relevant policy and create innovative ways of thinking.

Rules and strategies of the New Zealand Crippled Children Society and NZCCS in the 20th century and even CCS Disability Action in the 21st century have been touched especially by Social Role Valorisation (SRV). Normalisation and SRV theories were tools for professionals in the social services field regulating relationships between clients and professionals and justifying power structures behind the services.

Social Role Valorisation

Social Role Valorisation (SRV) was introduced into the disability discourse as a theory in response to devaluing treatment of disabled people particularly people with learning difficulties. Similar to other social and behavioural theorists, Wolfensberger (1998) applied behavioral and social learning theory initially to rehabilitation and then more broadly to explaining and promoting social norms in disabled populations considered to be deviant, devalued, or at risk for either. "Social Role Valorization (SRV) theory, building on the earlier politically disfavored ... normalization theory, suggested that there are socially valued descriptors that result in positive social and resource consequences" (DePoy & Gibson, 2011, p. 87).

SRV followed the normalisation theory developed by Nirje (1982) in Scandinavia in the 1960s. Normalisation theory built on the presumption that people with disabilities are living by the same normal rhythm as all other people. This includes all facets of life such as education, employment, housing, recreation and all social interactions. "The normalization principle means making available to all people with disabilities patterns of life and conditions of everyday which are as close as possible to the regular circumstances and ways of life or society" (Nirje, 1982, unpaginated).

SRV built on the normalisation principles and used them as its foundation. Thomas and Wolfensberger (1999) defined SRV as “the application of what science has to tell us about the enablement, establishment, enhancement, maintenance and/or defense of valued social roles for people” (Thomas & Wolfensberger, 1999, p. 125).

Most people have a number of social roles, highly valued or devalued; in the case of disabled people the process of devaluing has a long history in many societies and is often unconsciously applied by other members of that society. The example of the appalling treatment of Jews during the Nazi regime in Germany and the antisemitic propaganda leading up to the silent tolerance of the ‘final solution’, not only by parts of the German population but also by the Allies in displaying ignorance, is used as an example to demonstrate the power of policies which devalue certain groups in a society (Adorno, Frenkel-Brunswick, Levinson & Nevitt Sandard, 2001).

Disabled people have felt the force of being labelled the ‘Other’ over a long time and in many cultures.

If an individual fulfills expected social descriptive norms, he or she will be rewarded. Conversely, those who deviate from the norm will be devalued and excluded from opportunity. SRV theory contains both explanatory and prescriptive orientations that guide professional manipulation of unfavorable description. That is to say, devalued roles can be changed or valorized through teaching role normative behavior (altering observable description) or revising social norms (changing the exterior environment). (DePoy & Gibson, 2011, p. 87)

Aotearoa New Zealand examples of services using SRV are IHC’s services which supported People First self advocacy programmes (Vaccarino, 2010). CCSDA combines SRV with disability rights training to train staff who provide support services in the regions. SRV can be helpful in moving from

service provision to true support and partnership between disabled people and professionals (O'Brien & Sullivan, 2005; O'Brien & Murray, 1997).

However, one of the major criticisms of SRV by disabled people's groups is the suggestion of teaching role normative behaviour instead of altering the societal context which creates the devaluing circumstances. Another point of contention is the suspicion that SRV regards some people as having higher value than others. SRV is also criticised because it does not actively support independent self advocacy groups.

In contradistinction, Kendrick (2010), a non disabled writer on service provision for disabled people, defends SRV and portrays the theory as a contributor to significant social change regarding attitudes towards disabled people. According to Kendrick (2010), SRV theory has matured from a system of service delivery to a way of portraying how disabled people are forced into the role of the 'Other'. Ableism and Disablism present another perspective on the discourse about the norm and the 'Other' with a big emphasis on negative perception.

Ableism and Disablism

Both Ableism and Disablism theories offer similar interpretations of disability, the 'Other' and the norm and are often regarded as synonymous. Campbell (2008) makes the following distinction:

Disablism relates to the production of disability and fits well into a social constructionist understanding of disability. Ableism can be associated with the production of ableness, the perfectible body and, by default, the creation of a neologism that suggests a falling away from ableness that is disability. (Campbell, 2008, pp. 152-153)

Just as societies produce Racism and Sexism, disabled people as a minority group have to contend with Ableism. Campbell (2001) maintained that Ableism is:

A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human. (Campbell, 2001, p. 44)

Hahn (1986) described a close connection:

Between an attitude of paternalism, the subordination of disabled people and the 'interests' of ableism: Paternalism enables the dominant elements of a society to express profound and sincere sympathy for the members of a minority group while, at the same time, keeping them in a position of social and economic subordination. It has allowed the non-disabled to act as the protectors, guides, leaders, role models and intermediates for disabled individuals who, like children, are often assumed to be helpless, dependent, asexual, economically unproductive, physically limited, emotionally immature, and acceptable only when they are unobtrusive. (Hahn, 1986, p. 130)

Linton (1998) called Ableism a form of positive discrimination towards able-bodied people, her definition "includes the idea that a person's abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people" (Linton, 1998, p. 9). She also pointed out that Ableism is more difficult to define and many forms of hidden Ableism can be detected. Campbell (2008) identified the negative attitude of the ableist perspective:

The processes of ableism see the corporeal imagination in terms of compulsory ableness, i.e. certain forms of ‘perfected’ materiality are posited as preferable. A chief feature of an ableist viewpoint is a belief that impairment (irrespective of ‘type’) is inherently negative which should, if the opportunity presents itself, be ameliorated, cured or indeed eliminated. What remain unspeakable are readings of the disabled body presenting life with impairment as animating, affirmative modality of subjectivity. Instead of ontological embrace, the processes of ableism, like those of racism, induce an internalization which devalues disablement. (Campbell, 2008, pp. 153-154)

Rosenwasser (2000) defined “internalized oppression [as] an involuntary reaction to oppression ... which results in group members loathing themselves ... rather than realizing that these beliefs are constructed in them by oppressive socio-economic political systems” (Rosenwasser, 2000, p. 1). Ableism and internalised Ableism are thus exposed as socially created and have to be priorities in the DRM’s fight for acceptance of disabled people as part of the diversity in societies and for equal rights for disabled people.

Models and theories of disability have influenced the thinking around impairment and disability in society. In the next chapter the development of social policy and particularly disability policy is explored with emphasis on their philosophical foundation. Specific policies in Aotearoa New Zealand will be presented and put into the context of the thinking around impairment and disability at the time.

Chapter Four: Social history

Part 1: Key developments in social policy 1935-2008

In the first part of Chapter Four key developments in social policy and disability policy in Aotearoa New Zealand from 1935 to 2008 will be presented. In 1935 when the New Zealand Crippled Children Society was founded “the negotiation of disability policies between voluntary groups and the enhanced welfare state” (Tennant, 1996, p. 22) was the norm. In 2008 disabled people including the CCS DisabilityAction’s policy team in conjunction with disabled people’s organisations were active participants in governmental policy development.

Social policy and disability policy

Social policy is intentional, involves decision making and is described by Colebatch (1998) as “the exercise of authority to achieve collective purposes” (Colebatch, 1998, p. 42). Social policy has the well-being of citizens as its ultimate goal. Concepts of justice, equality, freedom, need, risk, and citizenship are the key themes used to evaluate well-being in this context (Cheyne, O’Brien & Belgrave, 2005). “Social policy is defined ... as actions that affect the well-being of members of a society through shaping the distribution of and access to goods and resources in that society” (Cheyne et al, 2005, p. 3).

Disability policy is broadly defined as social policy with two qualifications. First, there is the distinction that the target group are disabled people not the wider population and second, policy is judged by the degree to which it makes society less disabling in the lives of impaired individuals (Drake, 1999). Drake (2001) identifies the four orientations of disability policies as containment, compensation, care and citizenship.

The policy of containment led to the removal of disabled people from communities to hospitals, prisons or workhouses depending on being

assessed as deserving or undeserving poor. According to Finkelstein (1980) disabled people were historically included in village life and worked productively in their local communities. Mechanisation and the resulting greater speed of work during industrialisation led to the exclusion of disabled people and segregation from mainstream society was the result (Finkelstein, 1980).

The shift to compensation policy followed a proliferation of work injuries and the great number of soldiers returning permanently disabled from both World Wars in the 20th century. Disability was firmly located within the context of medicine and rehabilitation services and war pensions were some of the measures used to compensate people with impairments. The policy direction shifted to care as state programs such as day care and sheltered workshops were introduced.

The three policy models of containment, compensation and care interpreted disability as a personal condition and this was the prime focus of health and social services. The medical model regarded disabled people as defective and the goal was “to treat, ameliorate or ‘normalize’ according to prevailing understandings of physiological and cognitive norms” (Drake, 2001, p. 412).

Following other civil rights movements in the 1960s and 1970s, the Disability Rights Movement (DRM) gained strength in many countries and the United Nations declared the International Year of Disabled People in 1981. The field of Disability Studies as an academic discipline was developed by academics like Zola in the United States and Oliver and Finkelstein in Britain where the social model, naming disability as the result of social oppression in contrast to the impairment of the individual, was discussed widely (Zola, 1994; Oliver, 1990, 1996; Finkelstein, 1980). Drake (2001) highlighted responses to political pressure from radical groups and threats to the social fabric like protest and riot as an incentive to policy writing by welfare states. Civil rights were proclaimed as an entitlement and

experiences of disabled people provided the foundation for the delivery of disability services and policy development, not the opinion of the so-called professional experts. “A new civil rights paradigm is emerging in which the problems faced by disabled people are recognised as socio-political in origin” (Drake, 2001, p. 412).

The new civil rights paradigm was promoted by disabled people active in the political arena in Aotearoa New Zealand. According to the social model, society created a disabling environment and disability, consequently society had the responsibility to ensure policy which provided equal rights for disabled people (Oliver, 1996). Disability policy development based on inclusion and citizenship was championed by the social development approach introduced by the Labour-led coalition in 1999.

Geiringer and Palmer (2007) describe the key elements of the social policy framework in the era of the social development approach as the notion of well-being, level of well-being and its distribution, the social, legal and political freedom and aspects of culture and identity and the concept of social investment. Disabled people were involved in policy development and the government valued the partnership with disabled people in writing policy such as the New Zealand Disability Strategy (2001).

Although needs and rights-based approaches have a lot in common, the focus on rights differed conceptually from focus on needs and the rights-based approach created a language of empowerment. Geiringer and Palmer (2007) used the example ‘John needs food’ against ‘John has a right to food’ and highlighted the dichotomy of John as a passive victim and potential recipient of charity and John as a holder of entitlements. The rights-based approach eliminated the conundrum of the deserving and undeserving poor and justified positive discrimination leading to justification of allocating sparse resources to certain groups in society.

The next step is to look at the government approach to social and disability policy and at actual policies in Aotearoa New Zealand in the time from 1935 to 2008. The relationship between the New Zealand Crippled Children Society, NZCCS and CCSDA and the government of the time is an important component of the socio-historical perspective of this thesis and parallels between government policy and the organisation’s vision can be detected. A broad overview of some important government policies such as the Social Security Act 1938, the Disabled People’s Welfare Act 1975 and the United Nations Convention on the Rights of Persons with Disabilities 2007, to name a few examples, and their theoretical background between 1935 and 2008 is presented in Figure 2.

	Government approach	Policies
1935-1950	Welfare state	Social Security Act 1938
1951-1974	Rights Welfare State	Aitken report 1953 institutionalisation
		Burns report 1959 sheltered workshops
		DPEP Act 1969
		ACC Act 1974
		DPCW Act 1975
1975-1984	Economic interventionism	National Superannuation 1975
	Residual Welfare State	TOW 1975
1984-1999	Neoliberal approach	TOW Amendment Act 1985
	Residual Welfare State	Education Act 1989
		Human Rights Act 1993
		H&D services Act 1993
		1990s Deinstitutionalisation
1999-2008	Social development approach	ACC Act 2000
	Third Way	NZDS 2001
		NZSL 2006
		UNCRDP 2007

Figure 2: Policy development 1935-2008

Aotearoa as model welfare state 1935 to 1950

Social Security Act 1938

The political climate in Aotearoa New Zealand from 1935 to 1945 was characterised by the lingering effects of the depression, the election of the

first Labour government and its introduction of social welfare legislation, and the Second World War:

Nineteenth-century liberalism allowed only for minor intervention on behalf of individuals and focused on limited physical needs. The restricted provision of welfare was based on narrow moral judgements. When the first Labour government introduced its social security, full employment and state housing policies in the late 1930s, need had broadened to include psychological aspects of well-being, but the primary focus was on the domestic world of the family. Need was differentiated by gender and ethnicity, rather than based on universal human rights. (Belgrave, 2004, p. 25)

The concept of the Welfare State was introduced early in New Zealand with the creation of the Old Age Pensions Act in 1898, followed by the Pensions for Widows Act (1911), the Miners' Phthisis Act (1915) and the Pensions for the Blind Act (1924). The Family Allowance Act followed in 1926 and the first Labour government under Michael Joseph Savage secured all these advancements with the Social Security Act of 1938 combining it with public health care and education to provide 'from cradle to grave' protection for the population (Knutson, 1998).

The Social Security Act of 1938 introduced various forms of benefits including the Sickness Benefit. The Labour government had introduced an Invalid's Benefit in 1936 which provided for people with permanent impairments as long as they didn't receive the old age pension⁶. The Sickness Benefit catered for people who were temporarily unable to work because of sickness or accident. McClure (2004) identified "the way that needs were transmuted into welfare rights and linked to citizenship ... [as] the most significant feature of the Social Security Act" (McClure, 2004, p.143).

⁶ The recipient has to be at least 16 years of age and a permanent resident of Aotearoa New Zealand.

The principle of the Act, that the state would tax each person according to their means, and provide for each according to their needs, had fundamental implications for the disabled ... the interwar period was characterised by an expansion of income maintenance and of medical interest in disability. (Tennant, 1996, p. 21)

According to Tennant (1996) this had positive and negative implications for physically disabled people. There was “growing research and optimism about many conditions” but disabled people were looked at “in terms of specific functional impairment ... rather than as whole individuals” (Tennant, 1996, p. 22).

Soldiers returning from the Second World War with injuries and impairments prompted the Rehabilitation Act of 1941 providing land settlement schemes, job training and tertiary education. Organisations such as “the Disabled Servicemen’s Rehabilitation League had a particularly close relationship with government” (Tennant, 1996, p. 24).

From 1935 to the early 1950s the creation of the welfare state and rehabilitation policies for returned servicemen dominated the social policy environment in Aotearoa New Zealand. Societal changes in the post-war era led to many reports commissioned by government and later to the Disabled Persons Community Welfare Act of 1975.

Institutionalisation and community options 1950 to 1975

Disabled Persons Community Welfare Act 1975

The 1950s and 1960s brought rehabilitation for disabled people other than returned soldiers into focus and consumer advocate groups started to emerge lobbying against institutionalisation. The Aitken Report from 1953 disappointed consumer advocate groups such as the Intellectually Handicapped Children’s Parents Association (IHCPA) founded in 1949,

which had been a strong voice against institutionalisation. The Aitken Report recommended increased institutionalisation and extension of existing state institutions. “The main thrust was to endorse the concept of residential institutions and to encourage parents to place intellectually handicapped children in these institutions from about the age of five” (Millen, 1999, p. 25). The Aitken Report was controversial even in government circles (Millen, 1999) and the IHCPA continued lobbying against it.

It took only a few years until community living options were discussed. The Burns Report from 1959 criticised the findings of the Aitken Report, as well as government policies (Millen, 1999) and “recommended community options such as day programmes” (Stace, 2010, p. 20). In 1960 the Disabled Persons Employment Promotion Act enabled organisations to employ disabled people in sheltered workshops which Stace (2010) observed “was progressive policy for the time, although disabled people had no say in their participation” (Stace, 2010, p. 20).

In 1967 a Royal Commission presented the Woodhouse Report recommending compensation for all injuries on a no-fault basis which resulted in the Accident Compensation Act of 1972. The Royal Commission of Inquiry into Hospital Related Services in 1973 advocated for distancing services for disabled people from the medical model approach to moving into service provision in the community. In 1975 the Disabled Persons’ Community Welfare Act (DPCW Act) confirmed the right of disabled people to live in the community away from institutions, addressed some of the inequalities experienced by disabled people not covered by the Accident Compensation Corporation provisions and was based on a social model approach. Sullivan and Munford (2005) describe the DPCW Act as “emancipatory legislation for under it the control disabled people had over their lives was extended” (Sullivan & Munford, 2005, p. 24). The biggest change regarding the DPCW Act 1975 was that: “parts of the environment were to change to suit disabled persons: the longstanding assumption of

earlier policy had been that disabled persons should ‘fit in’ to their surroundings or decently hide themselves away” (Tennant, 1996, p. 27). In the next ten years economic turmoil changed the focus of government and social policy development was neglected in favour of economic policy but the principles of the welfare state were still regarded as important.

Economic interventionism 1975 to 1984

National Superannuation 1975

In December 1975 the Muldoon administration came to power and dominated New Zealand politics for the next nine years. Social policy development was pushed into the background and economic considerations were prioritised. It was the time of a world stagflation, the oil crisis, the loss of the UK market for New Zealand with the UK’s entry into the European Economic Union and the introduction of unfunded benefit schemes such as National Superannuation. Muldoon ignored the call for an economy determined by market forces. “Like the Third Labour Government that he regularly criticised, the Third National Government was equally convinced that New Zealand’s growth rate could be stimulated by selective interventions” (Bassett, 1998, p. 343). The business sector, treasury and many advisors suggested more flexibility, but Muldoon as Prime Minister and Finance Minister dominated economic policy making. “At the end of the 1970s political parties began to rethink their approach to the State’s responsibilities” (Bassett, 1998, p. 325).

In the early 1980s Muldoon, plagued by huge costs of the ‘Think Big’ energy projects and escalating inflation, forced a wage and price freeze⁷. It became clear that economic intervention was not an appropriate tool “to shield New Zealanders from the effects of many years of low commodity prices and the destructive efforts of governments to lessen their impact on living standards” (Bassett, 1998, p. 368). Between 1979 and 1984 New

⁷ “When the freeze was finally abolished at the end of 1984, inflation burst out and high interest rates rose even further. It took another six years to bring them under control” (Bassett, 1998, p. 368).

Zealand's political path moved towards more economic interventionism with the Supplementary Minimum Price scheme (SMP) protecting farm incomes from market swings being one example⁸.

Muldoon used his dominating personality and tactics against social unrest - such as the Maori land occupation at Bastion Point and the 1981 Springbok Rugby Tour - and he staged early morning raids on suspected Pacific Island overstayers, to distract from his mismanagement of the economy. Muldoon also led sustained attacks on beneficiaries such as solo mothers and the unemployed thus creating divisions in New Zealand society.

The major reason for the longevity of Muldoon's government was the introduction of National Superannuation soon after he took power replacing Labour's contributory superannuation scheme. The new scheme was funded by existing taxes and not means tested.

From 9 February 1977 the new scheme paid 70 percent of the average ordinary-time weekly wage for a married couple over 60 years of age, rising to 80 percent from 30 August 1978 ... 'National Super' payments were taxable. (Bassett, 1998, p. 345)

Tennant (2007) commented that the scheme made senior citizens a favoured group and encouraged the foundation of new non profit organisations such as Grey Power, which advocated for their constituency aggressively and reminded governments about their voting powers.

The economic turmoil set the scene for a major political change and the 1984 Labour government and the 1990 National government changed the political landscape forever. The finance crisis at the end of the Muldoon era provided a perfect springboard for radical changes in government policy and for the introduction of extreme neoliberal theory into New Zealand society.

⁸ "The gap between market realities and everyday farm experience kept widening" (Bassett, 1998, p. 353).

Neoliberal domination: Restructuring the state and welfare 1984 to 1999

Human Rights Act 1993, Health and Disability Act 1993

With the election of the Fourth Labour government in 1984, government policy changed substantially and the restructuring was to take the principle of individual choice to the extreme with emphasis on efficiency and accountability, individual rights and responsibilities. The neoliberal approach favoured cuts in public expenditure. Welfare provision was seen as contrary to economic development and the concept of a safety net reappeared. Skepticism towards state provision and emphasis on family responsibility ensured the efficient functioning of the market.

The reforms of the mid and late 1980s made the consumer the basic unit of social policy, replacing the idealised family of mid-century ... an emphasis on individual choice and consumption replaced the gendered, work-based understanding of the family as the central focus of social policy. (Belgrave, 2004, p. 36)

The Labour governments of 1984 and 1987 initiated a major restructure of all state funded services. “The reforms following 1984 were aimed at challenging the rights based paradigm that had developed in the 1970s” (Dalley & Tennant, 2004, p. 38). The growth of privatisation, corporatisation and rising unemployment marked the period.

New Zealand’s remarkable wave of public sector reform during the mid to late 1980s was the product of a unique convergence of economic pressure and political opportunism ... also important was the general ideological shift to the Right and the consequent preference for a smaller public sector and a more extensive reliance on market mechanism - contracting out, commercialisation,

corporatisation, and privatisation. (Boston, Martin, Pallot & Walsh, 1996, p. 16)

In the late 1980s successive governments started the radical restructuring of support services for disabled people. Economic deregulation ruled and the split between provider and funder in the service sector followed the restructuring in the health system. The separation of policy, regulation and implementation created quasi markets and contract state managerialism.

The new model of public management has placed a heavy emphasis on the separation of funders/purchasers and providers, and the separation of policy advice from policy implementation. It has also led to an extensive use of ‘contracts’ of various kinds to govern relationships, not merely between public- and private-sector organisations but also between (and within) public-sector organisations. (Boston, 1995, p. 79)

Government followed the ideology of managerialism which demanded ‘to let the managers manage’ in search for increased efficiency.

The managerial revolution was a deliberate attempt to bring non-clinical management into the social and health services. Managers were brought from the private sector and from a range of industries to inject rigour ... As a result professionals became increasingly isolated from the decision-making processes by the middle of the 1990s. (Belgrave, 2004, p. 38)

In the second term of the Labour government from 1987 the attack on welfare state provisions started. “Between 1987 and 1990 the welfare state was undermined by a piecemeal erosion, rather than wholesale demolition. The state remained the primary deliverer of housing, health and education”

(Kelsey, 1993, p. 82). The way to change the welfare state was signalled and the “National government would redesign the welfare state by placing responsibility back on people and their families” (Kelsey, 1993, p. 84).

The National government from 1990 started to dismantle the social welfare state and used benefit cuts to provide incentives for beneficiaries to seek work; work tests and lower benefits were part of the new policy direction (Lunt, 2008). The New Deal for People with Disabilities was introduced by the National government in the early 1990s. Throughout the 1990s concerns were expressed about government cuts of initiatives, which reduced social barriers experienced by disabled people. “ Voluntary sector reactions to the contracting environment moved from an initial nervousness to a crescendo of complaint by the late 1990s” (Tennant, 2007, p. 200). Government funding of support services for disabled people moved from the welfare agency (Department of Social Welfare) to health agencies (Regional Health Authorities) (“History of Disability”).

Jenny Shipley’s *Social Assistance: Welfare that Works* (1991) cemented the intention of government to withdraw from health and social service provision. Disability services were included in the Health and Disability Services Act of 1993. The disability support service component of *Vote: Health* included all provisions formerly covered by the Disabled Persons Community Welfare Act (DPCW, 1975) and funding was capped and ring-fenced. The liberation of disabled people from the medical system with its categorisation of conditions as promoted in the DPCW Act from 1975 was lost and disability was reintegrated into health. The Repeal of the DPCW Act “was a huge blow for disabled people as it symbolically marked the re-medicalisation of disability” (Sullivan & Munford, 2005, p. 24).

The 1993 Human Rights Act was important human rights legislation for disabled people. It’s main purpose was “to outlaw discrimination on a wide number of grounds and areas ... [and] to give meaningful legal recognition to the fundamental human right to be free from discrimination” (McBride,

2010, p. 286). Disability was added as a ground for unlawful discrimination, following lobbying by many disability rights groups and advocates including NZCCS with written submissions to the lawmakers.

In 1994 the needs assessment and service coordination (NASC) system was introduced and service provision was contracted to providers. “To access the system requires a diagnostic label (physical, intellectual or sensory), so once again the medical model reigns” (Stace, 2010, p. 22). In 2000 the Public Health and Disability Act confirmed “rationing and prioritisation” of services and equipment and “intensification of the measuring, assessing and dividing practices imposed upon disabled people” (Sullivan & Munford, 2005, p. 24).

The changes to the Accident Compensation Corporation started with the cut of lump sum payments in the 1992 ACC Act and continued with the opening up of the ACC scheme to private insurances in the 1998 Accident Insurance Act. Other policies affecting disabled people such as the 1989 Education Act and the 1985 changes to the Treaty of Waitangi Act (1975), which set up the Waitangi Tribunal, extending claims to 1840, have to be mentioned but are outside the scope of this thesis.

The alienation between managers, service providers and disabled people did not result in clearer vision of service needs and better accountability, but tipped the power balance in favour of the managers and service providers and left disabled people more powerless, struggling to survive economically. The growing discontent of disabled people’s groups with government policy and unease in New Zealand society about increasing poverty amongst lower socio-economic groups led to the election of a Labour-led coalition government and a new direction in government policy.

Towards inclusion: A Social development policy approach 1999 to 2008
New Zealand Disability Strategy 2001
UN Convention on the Rights of Persons with Disabilities 2006

The political climate in Aotearoa New Zealand changed in 1999 with the election of a Labour-led coalition government. The new administration embarked on the exploration of an innovative approach to social policy. The problem of low social investment was identified and focus was directed at increased public spending. Welfare payments were seen as an incentive and a trampoline not a safety net (Lunt, 2008).

Social policy with the goal of improving well-being does not intrinsically create conflict with economic development; rather the government seeks:

To harmonise social policy with economic development [by implementing] social programmes that make a positive contribution to economic growth and by advocating the allocation of collective resources for social investments that return resources back to the economy. (Midgley, 1999, p. 4)

The Third Way (Lunt, 2008; Giddens, 1999) was a new approach to social policy development avoiding the failed neoliberal path of Thatcher in the UK, Reagan in the US and Richardson in Aotearoa New Zealand and getting away from the traditional welfare state. It was favoured by Tony Blair's New Labour in Britain. Criticism on the Third Way approach to policy development pointed out that: "the Third Way enables centre-left governments to rationalise their role in consolidating neoliberalism" (Kelsey, 2002, p. 54).

The New Zealand Labour-led coalition government adopted a modified Third Way approach called the social development approach which had the promotion of an inclusive society as its goal. Disabled people gained access to education, employment and lifestyle choices like any other societal

group. Opening the labour market to disabled people not only created a favourable outcome regarding the quality of life, but made economic sense by tapping into an unused part of the labour force, reinforcing the desire of Third Way policy making to combine social change with economic advancement.

One of the first policy initiatives was the change back to the state as sole provider of workplace accident insurance in the ACC Act 2000. Followed by the most important New Zealand disability policy document in recent years in 2001, the New Zealand Disability Strategy (Minister for Disability Issues, 2001). The Disability Strategy's aim was to create a non disabling society in which full participation by disabled people is promoted and continually enhanced. The Strategy is a foundation paper for other disability policy development and for more detailed policy like Pathways to Inclusion (Department of Labour, 2001) and Opportunities for All New Zealanders (Ministry of Social Development, 2004). Similar to the Treaty of Waitangi principles which protect the right of Maori as indigenous people and are referred to in many policy papers, the New Zealand Disability Strategy (NZDS) advocates for inclusive policy for disabled people in Aotearoa New Zealand centred on the rights based approach. "Without Human Rights we cannot live as full human beings. Human rights include political, civil, social, cultural and economic rights" (NZDS, 2001, p. 4).

The social development approach and the social model constitute the theories underlying the Strategy and they are closely connected to Human Rights legislation such as the Universal Declaration on Human Rights (1948) and New Zealand legislation such as the Bill of Rights Act (1990), the Human Rights Act (1993) and the Privacy Act (1993). The Strategy emphasises the rights rather than the needs based approach highlighting the rights and responsibilities of citizens (Geiringer & Palmer, 2007).

Another important policy development was the Disabled Persons Employment Promotion (DPEP) Repeal Act (2007). The Act introduced a

minimum wage requirement for all workplaces signaling the end of sheltered workshops and other segregated employment.

In 2008 ACC launched the National Serious Injury Service (NSIS) promoting community inclusion of people with serious injuries such as spinal cord, traumatic brain injury, amputations and burns through services such as supported living and supported employment. This was a groundbreaking initiative helping to solve the discrepancy between entitlements for people categorised as disabled people and people regarded as having medical conditions.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) was crucial Human Rights legislation which will exert great influence on policy making and legislation in Aotearoa New Zealand. The chair of the committee for the UNCRPD was New Zealander Don McKay and disabled people from Aotearoa New Zealand played a crucial role in the development of the UNCRPD. The official delegation from Aotearoa New Zealand was the only one to have disabled people as members including a person with a learning difficulty. The signing of the UNCRPD was an important step forward for the rights of disabled people worldwide.

In 2006, The United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities. Its preamble recognises that disability is ‘an evolving concept’. The Convention defines ‘discrimination’ as ‘any distinction, exclusion or restriction on the basis of disability that has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.’” (McBride, 2010, p. 300).

New Zealand disabled people's groups such as DPA and People First and the policy team at CCSDA were involved in the writing of the Convention⁹. The ratification of the UNCRPD on the 26th of September 2008 was a major milestone on the way to equal rights for disabled people in Aotearoa New Zealand and the quick ratification in 2008 demonstrates the close cooperation of disabled people, disability organisations and the government of the time.

Disabled people's organisations are actively involved in monitoring the implementation of the UN Convention in Aotearoa New Zealand and part two of Chapter Four looks at the rise of advocacy and self advocacy groups, a pan-disability movement and disabled people's organisations monitoring the UNCRPD in Aotearoa New Zealand.

Part 2: Nothing about us without us

Opposition to the individual model and its interpretation of disability as a personal tragedy sparked the development of advocacy groups in the 1960s and 1970s and disabled people's journey to emancipation began.

Challenging their social and economic exclusion and exposing the ways in which medical rehabilitation and social welfare professionals stressed their functional and other limitations and general dependency, leading to widespread segregation in residential settings. (Barnes & Mercer, 2010, p. 24)

The fight for inclusion was conducted by disability rights activists fighting for equal rights, establishing independent living centers and by developing the thinking around disability with new models and theories of disability.

⁹ More detail about this involvement in Chapter Five: Documentary data, p.101.

Advocacy and Self-advocacy

The discourse around disability in the last 40 years was advanced by the Disability Rights Movement and the closely connected field of Disability Studies. The Disability Rights Movement (DRM), building on the thinking of other human rights movements around the world, developed their own analysis of disability as a way of emancipating itself from service provider organisations and state intervention. The academic field of Disability Studies was lead by disabled activists and academics at universities worldwide. Models and theories of disability originated from their combined work and developed as the Disability Rights Movement (DRM) grew in strength and influence.

The DRM in Aotearoa New Zealand and around the world used the phrase ‘Nothing about us without us’ to create a strong disability community and to lead the fight for equal rights in society. In 1998 Charlton used the slogan ‘Nothing about us without us’ as a book title stating that: “the slogan’s power derives from it location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice” (Charlton, 1998, p. 4).

The saying derived from the Latin ‘Nihil de nobis, sine nobis’ and is a direct translation. It was used by disabled people’s organisations around the world (Hermes & Rohrmann, 2006) and promoted the idea that no policy can be developed without full and direct involvement of the group which is affected by it and often the deliberate exclusion of other groups. Disabled people wanted to avoid making the same mistake as other rights movements who let advocates speak for them.

Social classifications of disability ranged from punishment by the Gods to the view of disabled people as seers and prophets; being regarded as objects of entertainment on medieval courts as court jesters and in 19th century fairs as exhibition ‘pieces’; and in the extreme as people possessed by demons (Sullivan, 1996). Fighting this mostly negative categorizing was one of the

reasons that disabled people wanted to be involved in all aspects of their own lives and reached even further.

In the last two decades, disability rights groups around the world have begun to use the phrase ‘nothing about us without us’ as a rallying cry ... This attitude demonstrates a greater desire to participate not only in decisions affecting their own lives, but in social issues that affect them as a group. A key element of the latter involves beginning to analyze how persons with disabilities are represented in society and working to move those perceptions in a more positive direction. (Jaeger & Bowman, 2005, pp. 111-112)

Charlton (1998) interpreted the phrase ‘Nothing about us without us’ by defining the meaning of ‘nothing’ as all the needs of disabled people in different cultural and socio-economic settings. Since the birth of the social model of disability, moving away from the medical interpretation of disability, people with impairments demanded the right to make decisions about their lives according to their experiences. The intellectual realisation created a Disability Rights Movement that:

Has developed its own ideology and politics. It is a liberation movement that is confronting realpolitik of the world at large. The demand ‘Nothing about us without us’ is a demand for self-determination and a necessary precedent to liberation ... the international DRM embraces ... independence and integration, empowerment and human rights, and self-help and self-determination.. ‘Nothing about us without us’ affirms the essence of these principles. (Charlton, 1998, p.17)

‘Nothing about us without us’ strengthened the awareness of having shared experiences and creates solidarity. It reinforced unity by fighting for the same social goals and for civil rights, against social exclusion and restricted access (Jaeger & Bowman, 2005).

Charlton (1998) connected the phrase with the organisation and politics of empowerment and the creation of a 'disability culture'. He emphasised the importance of the collective and individual element of the DRM and concludes that: "Nothing about us without us' represents the disability rights movement's vision of a new social order with changed attitudes towards disability and innovative use of resources" (Charlton, 1998, p. 17).

Early self-advocacy groups in Aotearoa New Zealand

Early self advocacy groups in Aotearoa New Zealand were influenced by similar movements in the USA and the UK. Campaigns by disabled people in the United States followed the civil rights movements of black people and women demanding equal opportunities and equal rights for their groups (Linton, 1998; Zola, 1994). Activists in Great Britain defined disability as social oppression and emphasised the distinction between impairment and socially created disability demanding social change (Oliver, 1996, 1990; Finkelstein, 1980).

According to Abberley (1987) the disability rights movement as a social movement was not only reacting to marginalisation, but also raised consciousness amongst its members and the wider population "as well as exploring and promoting different cultural values and norms in relation to disability than are evident in current dominant discourses" (Georgeson, 2000, p. 28).

An early forerunner of self-advocacy organisations in Aotearoa New Zealand was the Dominion Association of the Blind (1945) standing up against the patronising and domineering attitude of the New Zealand Institute for the Blind (NZIB). It changed its name to New Zealand Association of the Blind and Partially Blind in 1976 and later to Association of Blind Citizens of New Zealand Inc. (ABCNZ).

The International Year of Disabled Persons (IYDP) in 1981 was seen as the starting point for organised disability rights groups in Aotearoa New Zealand. The attempt by disabled people, disability consumer groups and service providers to work closely together brought differences to the fore¹⁰ and created conflict. Service providers initiated and accepted participation by disabled people, but wanted to retain the power to determine strategic direction and make major decisions. The time was right for the emancipation of disabled people's groups. Disabled people stood up against the patronising intentions of service providers who wanted to represent them on international bodies.

In 1978 [coordinating councils for the disabled] combined to become the New Zealand Coordinating Council for the Disabled (NZCD) and were soon at loggerheads with CCS and IHC who blocked their attempts to become the New Zealand representative on Rehabilitation International. (Sullivan, 2001, p. 97)

Other self-advocacy groups emerged and one of the groups was People First New Zealand in 1984 originally led by IHC but since 2003 an independent organisation. Deaf Aotearoa New Zealand (DANZ) (1977) promotes the interests of the deaf community, Nga Hau E Wha organises quarterly meetings for people affected by mental health issues and Ngati Kapo O Aotearoa Inc. (1983) is an organisation run by disabled Maori and their families providing health and disability services nationwide.

Pan-disability movement, 1983 DPA

In the early 1970s, Coordinating Councils for the Disabled were set up in Auckland, Wellington, Christchurch and Dunedin with the aim 'to coordinate the responses of the various groups of and for disabled people on issues such as education and access' (Sullivan, 2001, p. 97). The political climate was right for the development of a pan-disability group. The IYDP

¹⁰ See Russell Kerse comments regarding the IYDP in Analysis chapter, p.156.

in 1981, along with social unrest such as Bastion Point occupation in 1978 and the 1981 Rugby tour lead to a change in societal thinking. “The 1980s and early 1990s were characterised by transformations in social policy ... two key developments stand out: The first is the emergence of a much more vocal consumer voice; the second, the expansion of community care” (Tennant, 1996, p. 30).

The coordinating councils in the four main centres combined to form the New Zealand Coordinating Council for the Disabled (NZCD) in 1978 (Sullivan, 2001). Self advocacy groups for people with sensory impairments and learning difficulties were established and allied themselves with the pan-disability movement that resulted in a change of name with the establishment of the Disabled Persons’ Assembly (DPA) in 1983. “The Disabled Persons Assembly provided a focal point for the disability community from which to organize political action, and provided an opportunity for disabled people to build strength and unity amongst themselves” (Georgeson, 2000, p. 64).

Georgeson (2000) explains the process by which disabled people were sharing stories of their lives and 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 often have been socialized to believe ... Attitudes and misconceptions that prevailed about disability were beginning to be challenged by disabled people. (Georgeson, 2000, p. 54)

The International Year of Disabled Persons sparked emancipatory activities by disability groups around the world. For example in Germany the disability rights movement established self help independent living centres and started to develop the intellectual discourse about social discrimination

against the disability community. Koebse (2006) identifies the two directions of the German Disability Rights Movement:

The first was basically concerned with the establishment of infrastructure for disabled people like assistive services; the other was focused on the political representation of disabled people ... non-segregation, self-determination and being the expert of one's own life [are identified] as the central issues of the German Disability Rights Movement. (Koebse, 2006, p. 8)

The DRM in Germany is similar to the DRM in Britain in choosing the method of confrontation and political fight as the method of achieving equal rights for disabled people. In Aotearoa New Zealand, the country's small size aided connections between groups of disabled people and organisations engaged in disability service provision.

The DRM in Aotearoa New Zealand used 'Nothing about us without us' in different ways. "The Association of Blind Citizens of New Zealand Inc. adopted a self advocacy model from the beginning" (Disability Rights Promotion International, 2010, p. 27). This is in contrast to the DPA's pragmatic partnership approach involving disabled people, family whanau and service providers and the acceptance of theoretical foundations of self determination later. In 2001 DPA changed the membership criteria to giving the vote only to people who identify as disabled and their families following national and international examples (Disability Rights Promotion International, 2010).

From its inception, DPA aimed to be as inclusive as possible by creating categories of membership which would draw recruits from across the disability spectrum: individual, family, corporate and associate memberships. The vehicle chosen for achieving inclusion was the partnership model. (Sullivan, 2001, p. 97)

Sullivan (2001) presents the reasons for choosing the partnership model such as the acceptance of biculturalism as government policy in 1980 with partnership highlighted as the way forward in the relationship between Maori and Pakeha. Other reasons were the societal rupture created by the 1981 Springbok rugby tour with people consequently being cautious about confrontational movements. Sullivan (2001) mentions other reasons such as the belief that the goal of de-institutionalisation and entitlement for funded services, legalised by the Disabled Persons Community Welfare Act 1975, was easier to achieve by cooperation between disabled people and service providers. This egalitarian thinking was based on historical Labour principles and acknowledged the tight network in the disability sector in Aotearoa New Zealand.

But, for me, the real reason for DPA, opting for a consensual politics of partnership rather than a confrontational politics of self-determination, was their failure to do the intellectual work necessary for them to arrive at a clearly articulated position of what disability actually is ... other oppressed groups who separated themselves from their oppressors ... work out their analysis and strategy for action. (Sullivan, 2001, p. 99)

In the history section on DPA's website Quentin Angus, the first president of DPA, recalled the doubts about membership of organisations and their allocation of votes being raised in the 1990s. Originally organisations had two votes, individual members one; this was changed to one vote for all and the question if organisational member should have any influence on decisions about the lives of disabled people was discussed vigorously during the 1990s. In 2001 the DPA constitution was changed so only disabled people, the guardians of disabled children and organisations of disabled people are able to vote ("DPA: The Beginning"). This change indicates the growing confidence amongst disabled people to become true self-advocates.

Summary

The central issues of the DRM in Aotearoa New Zealand are still the promotion of true de-institutionalisation particularly for people with high and complex needs, guaranteed education and employment opportunities and campaigns for individualised funding of disability services with greater control by disabled people. Attention to cultural diversity is another crucial component. An important element of the work of the DRM today is the monitoring of the UN Convention with six disabled people's organisations engaged in this work: The Association of Blind Citizens, Deaf Aotearoa, DPA, Nga Hau E Wha, Ngati Kapo and People First.

Early advocacy groups of disabled people and families started to appear in the first half of the 20th century. The emergence of a pan-disability movement was aided by the establishment of disabled people's groups who wanted to represent themselves on the national and international stage. Conflict with service providers came to a head in the early 1980s resulting in the development of a pan-disability movement in Aotearoa New Zealand. The relationship of one of those service providers, CCSDA, to disability rights groups at different times of its history is explored next. The following chapter presents the foundation and development of the New Zealand Crippled Children Society, NZCCS, now CCSDA using documentary data.

Chapter Five: From the New Zealand Crippled Children Society to CCS Disability Action: Documentary data

This chapter draws on a number of documentary data to capture the changing contexts in the social and political development of the New Zealand Crippled Children Society from 1935 to 1945 and NZCCS and CCS Disability Action from 1997 to 2008. CCS Disability Action was founded as the New Zealand Crippled Children Society in 1935 and was modelled on international service clubs in particular North American Rotary clubs and their crippled children societies (Frost, 1960; Turner, 1944; Rotary Conference Proceedings, 1935). Over the next three decades the New Zealand Crippled Children Society consolidated its position as an important player in advancing medical treatment, rehabilitation and vocational training of ‘crippled children’ in New Zealand (NZ Crippled Children Society. History, 1984; Carey, 1960).

Following the neoliberal revolution of the mid 1980s and 1990s which introduced the contract culture, the power relationship between government and non profit organisations (such as NZCCS) changed and the division of funder and provider gave the State greater influence over service delivery (Tennant, O'Brien & Sanders, 2008; Tennant, 2007). The rise of the Disability Rights Movement (DRM) (Georgeson, 2000), Social Role Valorisation (SRV) theory (Wolfensberger, 1998), advocacy and self-advocacy theories (Ussher, 2003) and leadership by disabled people (NZCCS, 1995) created identity problems for the New Zealand Crippled Children Society. In the new century confirmation of Te Tiriti o Waitangi (1840) as a core document for New Zealand CCS, engagement in the creation of the New Zealand Disability Strategy (2001) and involvement of the CCSDA policy team in the writing of the UN Convention on the Rights of Persons with Disabilities (2006) confirmed the growing influence of disabled people on setting CCSDA's strategy.

A brief overview of the various names of the organisation, services provided, visions followed at different times and of the approach taken relating to Maori is provided in Figure 3. This relates back to Figure 2 (p. 57) where key policies of the different eras are listed. The dates are different in both figures because this thesis highlights the first decade and the last 11 years of the New Zealand Crippled Children Society and CCSDA respectively, but key policies presented in Figure 2 (p. 57) cover the period from 1935 to 2008.

	Name of organisation	CCSDA services/ vision	CCSDA & Maori
1935-1945	New Zealand Crippled Children Society	Care for crippled children	Attempts to include native children
		Rehabilitation	
1946-1997	New Zealand Crippled Children Society	Extension of services	
		Extension of client base	
	1989 New Zealand CCS	Consumer Group SRV staff training	Treaty of Waitangi as core document
		Contract culture	
1997-2008	New Zealand CCS	Millennium Charter	Bi-cultural structure for organisation: Pukenga Rangatira Te Waka Whakapakiri
			Koeke Tamata
		2007 CCS Disability Action	Local approach to Maori tikanga
		Collaboration with DRM organisations	Combination of Maori voice and disability rights voice

Figure 3: CCS Disability Action 1935 - 2008

The documentary data used include: Annual Reports (1935 to 1945 and 1997 to 2008); Rules of the Crippled Children Society(1940); the Millennium Charter (1997); Strategic Directions and Policies of CCS Disability Action, 2009-2014; and submissions to government on policies and human rights legislation, often written in conjunction with disabled people’s organisations such as DPA and People First. The reason for using these particular documents is their relevance in the context of the different

eras, highlighting the development of the strategic thinking of the New Zealand Crippled Children Society, NZCCS and CCSDA at various times.

The beginnings: New Zealand Crippled Children Society 1935 to 1945

New Zealand experienced two major polio epidemics in 1916 and 1924/25. In 1930 Alexander Gillies (later Sir), a Wellington orthopaedic surgeon inspired the Wellington Rotary club with his speech about 'The Cripple, and Vocational Training for the Physically Defective' in which he presented his vision of possible rehabilitation of children affected by polio or infantile paralysis.¹¹

Dr. Gillies was concerned about the lack of follow-up treatment in the health system for children affected by polio and "urged the need for specialised treatment of cripples and later training for future citizenship" (Carey, 1960, p. 4). Dr. Gillies advocated strongly for the establishment of an organisation to provide follow-up care and employment and lobbied members of Rotary Clubs, especially the Wellington Rotary Club.

In every scheme relating to the treatment of cripples, there were four headings: (1) Prevention, (2) after-care, (3) training, and (4) employment ... This country educated them up to 14, but after that in many cases, overlooked the cripple entirely and gave no thought to his training and the question of his employment. (Frost, 1960, p. 79)

Because of the influence of the worldwide recession on the New Zealand economy and consequent demands on Rotary Clubs there was a delay until 1932 before the Rotary National Conference adopted the resolution: "That it be a recommendation to each Rotary Club to form a committee for the purpose of enlisting the interest and support of the entire community in the problem of the cripple" (Frost, 1960, p. 48). Finally, following the example

¹¹ The estimated number of children with polio in New Zealand was 5000.

of American Rotary clubs,¹² the New Zealand Crippled Children Society was launched at the district conference of Rotary clubs in Timaru in February 1935; Rotary approved the draft constitution and rules of the Society and donated £800 (Conference Proceedings, Timaru, 1935 as cited in Frost, 1960).

In March 1935 Viscount (later Lord) Nuffield, a prominent English industrialist, donated funds to support the work of the New Zealand Crippled Children Society. The Evening Post on the 5th of March 1935 reported that Lord Nuffield, better known as Sir William Morris, donated £50,000 for the crippled children of New Zealand:

There is one thing I want to do before I leave New Zealand, and that is to help the same as I have helped in the Old Country ... When I think of crippled children, I thank God that I was not born a cripple myself. I cannot imagine anything more dreadful than being born a cripple, and having no one to put me straight.
(Frost, 1960, p. 83)

Lord Nuffield's generosity inspired Mr. and Mrs. Wilson to gift St. Leonards, their Takapuna residence on 13-acres with commanding views of the Rangitoto Channel, the Hauraki Gulf and the coastline for the use of crippled children (Frost, 1960). Viscount Nuffield gave another £10,000 with the interest earmarked for the running and maintenance of the Wilson Home; in 1936 the money was passed on by the Auckland Crippled Children Society to the Auckland Hospital Board which was responsible for the management of Wilson Home.¹³

¹² The first Crippled Children Society in the USA was formed in 1913 by the Rotary Club of Syracuse.

¹³ Following Lord Nuffield's donation Mr. Norwood, past president of Wellington's Rotary Club and later president of NZ Crippled Children Society announced a £100,000 legacy given to establish a home for crippled children by Mr. H. S. Dadley in 1933 (Frost, 1960, p. 50). The money from the Dadley Trust for Crippled Children was later used to build a National Centre for Crippled Children in Mount Street in Auckland.

The inaugural meeting of the New Zealand Crippled Children Society Inc. was held in Wellington on the 9th of July 1935 with 17 branches represented by delegates from Auckland, Blenheim, Christchurch, Dannevirke, Dunedin, Gisborne, Hawera, Invercargill, Masterton, Napier, Hastings, New Plymouth, Nelson, Oamaru, Palmerston North, Timaru, Wanganui and Wellington. Branch levies were set at 10% of annual membership subscriptions excluding life members and donations. The boundaries of the branch districts were based on the boundaries of hospital districts and the way the Society would function was described in the resolution:

That the work of the Society be carried on by means of the closest cooperation with the Government Health and Educational authorities, Hospital and Education Boards, and with all other kindred agencies or organisations engaged similarly in social and welfare work in the community. (Frost, 1960, p. 98)

The Evening Post reported on the 9th of July that His Honour Mr. Justice Smith was elected president without opposition ... In his acceptance speech he reiterated that:

The inauguration of the Society was due to the Rotary Clubs, and was a striking example of the good the Clubs could do. Crippled children were the wastage of peace. The nation honoured its war cripples, and it was gratifying to know that much was also done for the cripples of peace. (Frost, 1960, p. 96)

The general aim and policy of the new Society was to be directed towards:

The needs of crippled children in New Zealand and in devising ways and means of ameliorating their position in the treatment of the disability (medical, curative or otherwise); in educational and vocational training; in finding suitable avenues of employment; in removing any existing bars to employment of cripples; and generally

in showing a friendly care and personal interest in every way possible in the condition and circumstances of all crippled children and their future. (Carey, 1960, p. 7)

The following definition of a 'crippled child' was adopted at this first meeting:

A crippled child is a person under 21 years of age, who, not being mentally deficient has a defect which causes or tends to deformity or interference with normal function of the bones, muscles or joints; the defective condition may be congenital or acquired but does not include defects of the vital organs. (Carey, 1960, p. 20)

The New Zealand Crippled Children Society focused on physical impairment caused by polio following the lead of Rotary Clubs in the USA and their establishment of Crippled Children Societies. Another reason was the acceptance of physical impairment in society as a worthwhile cause in contrast to an aversion against intellectual impairment relating to societal thinking of the time (see interview data in Chapter Six, pp. 120-121).

In 1936 the first AGM was held in Wellington with 16 branches attending. The New Zealand Crippled Children Society had researched the numbers of children in each branch and 1409 children were registered with the Society throughout the country, only a fraction of the 5000 children affected by polio at the time. Vocational training was provided in different skill areas for boys and girls and in 1937 a trial scheme was funded in Manawatu and Taranaki to explore 'ways and means of assisting Native crippled children' (Third Annual Report 1937/38). The programme for 1938/39 included:

Continuing to give the same opportunity to every crippled boy or girl as that afforded to physically normal children ... maintaining a general programme of educational publicity and making the

community conscious of the problem of the crippled child ... (and) to wage war on infantile paralysis. (Third Annual Report, 1937/ 1938)

In 1939 travelling orthopaedic clinics were established to serve especially rural areas and Lord Nuffield donated a further £7,500. Sir Alexander Gillies had earlier suggested to divide the cases of 'crippled children' into two classes 'those in the country and those living in the city' and the goal was:

To place every child within reach of existing surgical and medical aid by arranging to provide the necessary transport and to place within reach of every crippled child a sound vocational training, so as to fit it to take its proper place in society, and in the economic life of the country. (Frost, 1960, p. 92)

To achieve the detection of all 'crippled children' the founders acknowledged the importance of a link between families and the Society. Welfare officers, renamed Field officers in 1949, soon complemented the work of volunteers.

The importance of welfare work in surveying branch districts and establishing liaison with hospital authorities, members of the medical profession, employers, the Labour Department, Education authorities, etc., is proving an important part of the work of the Society. (Annual Report, 1939/1940)

There was no professional social work training available before 1949 when "the university college of Victoria, Wellington ... provided the first (and, for twenty years, the only) professional course for social work education and training in Aotearoa New Zealand" (Nash, 1998, p. 5). In the early years of the New Zealand Crippled Children Society Field officers qualifications "would be the better for teaching or nursing experience, but must have chiefly common sense and sympathy" (Carey, 1960, p. 51). "In the years

before New Zealand had its own social work course, these professions [teachers and nurses] provided the next best preparation for work in the social services” (Tennant, 2007, p. 78).

In the late 1930s other impairments besides polio were included in the services. There were 2193 children registered nationwide covering 13 different impairments including cleft palate and cerebral palsy. Reluctance of Maori to send children away for treatment was noted and a long term plan including radio broadcasts in Maori and English were suggested. In 1941 the New Zealand Crippled Children Society donated £250 to each of the main hospitals for provision of special equipment for use in craft centres for occupational therapy purposes for children (Annual Report, 1941/1942).

The division of tasks between the State and the organisation was clarified at the end of the decade. “The function of the State [is] to care for the crippled child; it was the special privilege of the Society to look after the interests of the crippled child” thus highlighting the advocacy role of the Society (Fifth Annual Report, 1939/1940). The Programme for 1939/1940 reads like a mission statement and offers a definition of voluntary organisations and their relationship to health and welfare provision by the State:

From the point of view of the voluntary organisation there are those who protest that the voluntary organisation is out of place in work which is the duty of the State to under take. To them the word ‘voluntary’, in such a connection suggests a condescending benevolence which is wholly distasteful ... In these days of systematized efficiency the voluntary organisation does not represent, as some people seem to suppose, the inexperienced efforts of an assembled group of amateur philanthropists. Rather is it the means by which skilled pioneers are free to prepare the way for the State’s subsequent advance, and experienced workers are provided to cover ground which, open as it is only to the personal touch, must always remain outside the official province ... Such an

organisation as ours, keeping as it were, a little ahead of the State and taking advantage of its independence, can investigate and try out new methods alike in the sphere of clinical work and of the training and employment of the disabled. (Fourth Annual Report, 1938/1939)

Vocational training was provided and encouraged, so that disabled people were not reliant on benefits. As it was stated in the Seventh Annual Report the climax is reached if a cripple is “able to take his place in the world as a self-supporting citizen” (Annual Report 1941/1942).

The second World War interrupted the work of New Zealand Crippled Children Society; transport difficulties caused by the war in the Pacific caused cancellation of annual conferences in 1942 and 1944. The New Zealand Crippled Children Society worked closely with the government of the time aided by the promotion of Peter Fraser to Prime Minister in 1939; Peter Fraser had been very supportive previously when he was the Minister of Health.

Close cooperation between the State and the New Zealand Crippled Children Society was a major goal of both sides and at the 1943 annual conference the Minister of Health, Arnold Nordmeyer, praised the organisation in his speech as “the youngest philanthropic organisation in New Zealand” highlighting travelling clinics, occupational therapy, vocational guidance and educational work. He stated that the good work in the branches leads to a “national movement which would place the Society in the forefront of institutions in New Zealand” (Ninth Annual Report, 1943/1944).

The year 1945 marked the end of the first decade of the New Zealand Crippled Children Society. The founders of the Society were pleased with the progress made with identifying and supporting children in need. Medical practitioners offered their services, often pro bono, and a positive attitude towards medical advances especially in the field of orthopaedic surgery

added to the optimism and the belief in rehabilitation. Innovative surgery pioneered overseas was trialled in Aotearoa New Zealand with the financial support of the new Society. Cooperation with the State was very successful and the Society regarded it's work as ahead of State provision introducing new ideas. Major donations by benefactors, both local and international, at the time of the Society's foundation secured independence and financed the creation of services such as traveling clinics, subsidies for occupational treatment at hospitals and vocational training (Annual Report, 1941/1942).

The philosophy underlying the work of the Society was the medical model of disability in unison with the dominating thinking of the time. Impairment was approached in two ways: first, the belief that medical advances can deal with and sometimes cure some conditions by surgery, physiotherapy, hydrotherapy and other new methods. Second, the attitude of the family towards their 'crippled child' has to be guided and the advice of professionals has to be followed. Another element was the rather innovative desire to educate communities about the need of 'crippled children' and provide training and employment for young people and adults with impairments. The Society's philosophy did not encourage the use of benefits introduced in the Social Security Act 1938 but endeavoured to get disabled people into work in local businesses. The era of sheltered workshops was to come in the 1960s (Stace, 2010).

In tune with contemporary attitudes, the founders' generation shows a paternalistic and rather patronising 'we know best what's good for you' approach, but the good intentions behind their work cannot be denied (Tennant, 2007; Sullivan, 2001). The New Zealand Crippled Children Society brought medical practitioners, rich philanthropists, politicians and church leaders together around a common cause and aided the national and international networking of the higher socio-economic classes in Aotearoa New Zealand.

The intervening years: 1946 to 1997

Extension of client base and services 1946 to 1981

In 1948 the Society funded a visit by Dr Earl Carlson, who lectured about Cerebral Palsy and wrote a report for the Minister of Health. His inspirational visit - Blackwood (2001) describes Carlson's visit as a turning point in his life¹⁴ - initiated a trust fund for children with Cerebral Palsy and a five year plan for the care of people with Cerebral Palsy thus extending the client base of the New Zealand Crippled Children Society.

One of the council's final actions in 1948 was to suggest that a joint statement by the Society and the State be issued to the Press showing some of the features of a five-year plan for dealing with cerebral palsied children and adolescents. (Carey, 1960, p. 49)

Sir Charles Norwood, New Zealand Crippled Children Society's president since 1939 established the Norwood Trust for children with cerebral palsy in 1950, then the Spastic Fellowship in 1951. Services for people with cerebral palsy were separated from the New Zealand Crippled Children Society and the Spastic Fellowship was renamed The Cerebral Palsy Society of New Zealand Inc. in 1984.

The New Zealand Crippled Children Society spread geographically establishing a branch in the Cook Islands in 1951. With the Aitken Report in 1953, institutionalisation of disabled people was on the agenda of the government (see Figure 2, p. 57) and was taken up by the Society. The Annual Report of 1953/1954 mentioned "problems with chronic cases" and the Annual Report from 1954/1955 states: "Branches of the Society have been concerned regarding the future of chronic cases registered with the Society who will require some form of residential hospital or hostel accommodation".

¹⁴ Blackwood, J.W. (2001). Rich and rewarding: An autobiography/Bill Blackwood.

The Wilson Home in Auckland provided accommodation for ‘crippled children’ after operations and for - often long term - respite. The cooperation between the New Zealand Crippled Children Society and Hospital Boards was working well and in 1957 the Pukeora Home for Physically Handicapped Young was opened, administered by the Waipawa Hospital Board. The move towards institutionalisation was supported by the Society and the medicalisation of disability is apparent in the cooperation between the Society and Hospital Boards (Tennant, 2007; Annual Report 1954/1955).

The appointment of William Herewini as the first Maori representative on the National Council of the New Zealand Crippled Children Society in 1960 and the appointment of the first Maori Field Officer at the Auckland branch in the 1960s was seen by the National Executive as an innovative step acknowledging the importance of Maori involvement (New Zealand Crippled Children Society History, 1984). Critical historians such as Belgrave (2004) and Tennant (2004) however regarded it as a reflection of the ‘Zeitgeist’ as Maori communities were forced to assimilate more fully into the Pakeha world (Belgrave, 2004). Urbanisation of Maori in this time period made “the organisation of services for Maori ... more important during the 1950s as a demographic revolution of unprecedented proportions was taking place” (Tennant, 2004, p. 33).

In the 1960s recreation was acknowledged as an important component of the New Zealand Crippled Children Society’s work. The trend spread into New Zealand’s society with the formation of the Halberg Trust for Crippled Children in 1963 and with Outward Bound offering the first course for people with disabilities in 1976. Worldwide disability sport as a rehabilitation tool saw the first Paralympic Games held in Israel in 1969. New Zealand Crippled Children Society made a grant of \$500 supporting a New Zealand team at the Paralympic Games where Eve Rimmer won four medals (New Zealand Crippled Children Society History, 1984, unpaginated).

Initiatives in the 1970s concentrated on improved accessibility to the built environment and transport. Russell Kerse, National Service director at the time, advocated intensively for access provision to be included in the Disabled Persons Community Welfare Act of 1975 (Beatson, 2001). The Operation Mobility parking scheme was launched in 1977 and the Barrier Free campaign began in 1979.¹⁵ In the same year the New Zealand Crippled Children Society's national office moved into fully accessible premises in Vivian Street, Wellington (New Zealand Crippled Children Society History, 1984, unpaginated).

The following years signalled a new era in New Zealand Crippled Children Society's history with fundamental changes to the relationship between the State and non profit organisations.

Service development and contract culture: NZ CCS 1981 to 1997

The 1980s were dominated by policy work in response to government initiatives using the neoliberal approach (see Figure 2, p. 57) and in 1984 the manuscript of a history of the organisation was published internally without specifying an author other than the NZCCS Information Service. The 1984 History described the organisation and its national and branch components:

Through its National Office in Wellington, the Society acts as the coordinating body for its members - the twenty-one Crippled Children Society Branches and their related sub-branches and sub-centres covering the whole of New Zealand and the Cook Islands ... National Policy is set for the Society by a biennially elected Council after consideration of any National Office or Branch recommendation ... The National Office is the working arm of the New Zealand Council ... Each Branch is independent and autonomous in its own ... Branches are independent of government funding except for

¹⁵ The campaign included work towards an architectural award for accessible housing.

subsidies toward certain capital works and towards some salary costs for specialist services. (New Zealand Crippled Children Society History, 1984, unpaginated)

The New Zealand Crippled Children Society concentrated initially on activities for the International Year of Disabled Persons in 1981 including a nationwide Telethon which had a negative financial effect on the Society as people donated to Telethon rather than to the New Zealand Crippled Children Society's annual appeal and only 4% of the Telethon funds were distributed to the Society (New Zealand Crippled Children Society History, 1984).

In 1981 the publicity department in the National Office initiated disability awareness programmes¹⁶ including the 'Kids up the Road' puppet programme. "The team of six muppet style puppets were originally purchased from the USA after the Society became aware of an educational programme being run by Washington group, 'Kids on the Block Inc' " (New Zealand Crippled Children Society History, 1984, unpaginated). The following year the education programme was co-sponsored by the Accident Compensation Corporation and some members of the National Executive such as Russell Kerse voiced criticism regarding the disability awareness content of the programme. The 1984 History justified the new approach:

The CCS 'Kids up the Road' puppet education programme carried a new message to primary school pupils throughout 1982. The theme was accident prevention ... new puppet characters and scripts were created in association with ACC, cosponsors of the year's programme. While the approach to getting the integration and awareness message conveyed to school children was treated differently, the message relating to the disabled, was always

¹⁶ In 1984 a 13 part TV show 'Kids from Owl' featuring disabled children screened on NZ TV.

consistent. (New Zealand Crippled Children Society History, 1984, unpaginated)

In 1984 a long term plan detailing development of services and other initiatives for the National Society was developed in response to the election of Lange's Labour government signalling a new approach to social policy. There are hints of conflict caused by Disability Rights groups arguing about direct representation of disabled people on the international stage (Sullivan, 2001) and subsequently the establishment of the DPA in 1983, the first pan disability organisation in Aotearoa New Zealand.

NZCCS responded to changes in social policy in the 1980s (see Figure 2, p. 57), which put emphasis on individual choice, with extending the range of people involved in determining the principles and the vision. Nancy Barnett was the first woman elected to the National Executive Board in 1986 and 'consumers' - as disabled people were labelled in annual reports now, following the market oriented ideology of the time - were officially invited to participate in the AGM for the first time. In 1987 a new Mission statement and Philosophy and Policy documents were adopted by the National Council highlighting the move to a consumer driven organisation with:

Increased emphasis on empowering people with disabilities and inviting their involvement in the management of the Society. The goal encourages more control of their own lives and full membership in the community. The original concept of a charity has long been outgrown. (as cited in: On the Move, 1995, unpaginated)

In 1985 the 50th Jubilee of the New Zealand Crippled Children Society was celebrated and promoted as a 'Golden Opportunity'.

In the last fifty years the activities of the Crippled Children Society have expanded far beyond those originally envisaged by its founders.

Today it has outgrown its image as a 'charity' and become an innovative and supportive rehabilitation organisation maintained by funds provided by all sections of the community. (New Zealand Crippled Children Society History, 1984, unpaginated)

Tennant (2007) describes the societal mood reflected in non profit organisations in the late 1980s:

Consultants and change managers, mission statements, brand identities and empowerment models, bicultural journeys, quality assurance and assertions of excellence: the mantras of the late 1980s and 1990s are striking to anyone studying the records and annual reports of voluntary organisations ... Organisational names were changed, often to snappy acronyms conveying 'brand identities'. (Tennant, 2007, p. 193)

Following societal trends the New Zealand Crippled Children Society adopted a new name and logo changing to New Zealand CCS in 1989. The title National Director changed to CEO in 1992 signalling a more corporate style of operation.

Following the bicultural Zeitgeist and with encouragement from funding criteria, partnership with Maori as Tangata Whenua was actively pursued starting with the recognition of the Treaty of Waitangi as a core document for the organisation and acknowledging the importance of Te Reo which had been declared the second official language of Aotearoa New Zealand in 1987.

It took another two years before the Society formalised the partnership with disabled people. A consumer working party was established in 1989 to ensure the growth of consumer involvement in all facets of the New Zealand Crippled Children Society. The power balance between the State and the

organisation had changed with the introduction of contracts resulting in increased competition between non profit organisations.

The disadvantage experienced by disabled people resulted in NZCCS paying more attention to Human Rights legislation and a submission advocating for the addition of disability as a factor of discrimination to the Human Rights Act 1993 was written. Core Beliefs and Values of New Zealand CCS were named in the Annual Report as “individual worth and dignity, self-determination, independence, choice and community integration and participation” (NZCCS Annual Report, 1993).

The 60th anniversary of the organisation prompted a pictorial history named *On the Move: 60 years of CCS* published by the National Office in 1995. The publication highlighted the importance of independence for disabled people and demonstrated achievements by individual disabled people connected to the organisation. It stressed the move toward biculturalism and advocacy in the public sphere as crucial elements, but did not mention rising tensions. The conflict between neoliberal government policy with cuts in funding for support services for disabled people and the vision of NZCCS to ensure community participation and equal rights for disabled people became apparent. The rise of an independent disability rights voice in conflict with service providers added another element to the history of NZCCS.

Millennium Charter: New Zealand CCS and CCS Disability Action 1997 to 2008

The welfare reforms from 1991 and the rule of the contract culture prompted a major restructure of New Zealand CCS (see Figure 2, p. 57; Figure 3, p. 80). The Millennium Charter was released in 1997 determining rules for the partnership between individual branches and the National Society, referred to as ‘the parties’. The Charter introduced the Carver model of policy governance with clear separation of management and governance (Carver, 2006). Individual branches and the National Society, all

separate legal entities, acknowledged the need for consistent nationwide services with a tighter delivery structure. Larger regions uniting individual branches, shared strategic priorities and acceptance of the Treaty of Waitangi as a core document of the organisation are other main objectives of the Charter.¹⁷

In signing this Charter, the parties accept that they are making a commitment to consistent, quality minimum standard of services on a nationwide basis, ensuring these services are sensitive to all cultures, and that local and regional differences will be resolved with reference to that objective. (New Zealand CCS Millennium Charter, 1997)

As a result of the Millennium Charter, restructuring into 7 regions with 16 branches (Nelson and Marlborough as well as Tairāwhiti and Hawke's Bay merged two branches into one) took place. Local branches remained legal entities but local Boards were replaced by Local Advisory Committees (LAC) and Local Executive Committees (LEC). LACs were charged with contributing innovative ideas to branches and strengthening participation by disabled people locally, and LECs with fulfilling the task of guarding branch assets and investments and funding necessary services identified by LACs. New constitutions were confirmed at the national and all local AGMs. The Wanganui branch dis-associated itself from the national organisation because of disputes about the distribution of funds donated locally.

An administration and management review including the appointment of regional managers in the seven regions and service team leaders in the 16 branches took place in 1999 and a new service development structure was established in 2000. This development brought the changes resulting from the signing of the Millennium Charter by branches and national society to its conclusion.

¹⁷ More about the changes in the non profit sector in the analysis chapter.

The partnership with Maori grew stronger and 1998 marked the establishment of the National Bicultural Strategy with the intention of creating a parallel Maori structure of NZCCS. The role of Kaitohutohu was created and the following year saw the development of Terms of Reference for Te Waka Whakapakari, the Maori arm of the management structure completed. Pukenga Rangatira was established as a parallel governance arm with the intention of engaging Maori kaumatua and kuia nationwide. The management arm was accountable for monitoring services to Maori and reporting to Pukenga Rangatira. A further restructure led to the establishment of Koeke Taumata combining Pukenga Rangatira and Te Waka Whakapakiri in 2005 and a Maori kaumatua from this group joined the National Board (NZCCS, Annual Report 2004/05).

Another important development was the closer cooperation with the government. The Labour-led coalition government elected in 1999 signalled a major change in policy development and the new government created a Ministry for Disability Issues as promised in the election campaign. NZCCS welcomed the 1999 Labour government's social development approach to policy and Pat Hanley, National Service and Policy Manager commented on the disability policy direction of the new government:

CCS was very pleased to see the appointment of Hon. Ruth Dyson as Minister responsible for Disability Issues ... CCS looks forward to working with the new government to ensure that disability issues are afforded the attention and resources necessary to advance the well-being of people with disabilities. (NZCCS, Annual Report, 1999)

One of the first initiatives regarding disability policy was the establishment of an advisory group to assist in the writing of the New Zealand Disability Strategy (NZDS, 2001). Following a crucial component of the social development approach's philosophy, people affected by policy had to be closely involved in its creation. The NZDS cemented the rights of disabled

citizens regarding inclusion in all aspects of society and paved the way to more inclusive practice in Aotearoa New Zealand and for its key role in the development of the UN Convention for the Rights of Persons with Disabilities (2006).¹⁸

Following the release of the NZ Disability Strategy in 2001 New Zealand NZCCS reviewed the strategic directions and placed emphasis on three service areas: children and families, youth and adults and community development. The Supported Lifestyles service signalled a new way of working with children and families and disabled adults. Innovative campaigns used new media such as YouTube to promote accessibility to the environment, mobility parking and non discriminatory language as pathways to an inclusive society.

Campaigns and new initiatives from 1999 to 2008

Several campaigns and new initiatives were launched from 1999 to 2008. The big themes of disability awareness, early intervention and accessible communities remained. One of the campaigns, however, was controversial and parts of the organisation refused to cooperate because members did not regard campaigns promoting the prevention of impairment as core business of NZCCS.

This campaign, the Folate Campaign, was launched in 1999 by the National President of NZCCS. The campaign lobbied for the introduction of folate in all commercially baked bread to foster folate intake of pregnant women and prevent babies being born with neural tube defects. The Annual Report from 1999 presented the National Folate Awareness campaign as a “significant success”:

In 1999, its first year, we increased awareness of the role of folate 15 percent nationally among women of childbearing age ... I must stress

¹⁸ See ‘campaigns and new initiatives from 1999 to 2008

that this campaign is not about devaluing people with disabilities many of our consumers have Spina Bifida. It is about New Zealand women having access to this information so they can make an informed choice. (President's Report, NZCCS Annual Report, 1999)

Other campaigns such as 'What did you say?' (2002) consisting of booklets for professionals with acceptable language regarding impairment and disability was welcomed by all members and was especially successful with health sector professionals.

The intention of the campaign 'What did you say?' was announced in the 2001 Annual Report:

In our communities and nationally we regularly hear phrases describing people 'suffering from disabilities', 'wheelchair bound', 'handicapped', 'dependent'. It is our role to change this thinking and dissolve the discriminatory language and behaviour that disabled people face every day ... We need to be more proactive in reasserting the empowerment model, and to bring our benefactors along with us. (President's Report, Annual Report, 2001)

'Let's get in Early' (2005), a campaign launched at parliament with information packs for new parents of disabled children, offering early support, reinforced NZCCS's commitment to children and families.

Campaigns such as 'Moving around Communities' (2005), which promoted accessible environments and 'Caught' (2006), which lobbied for the correct use of mobility parks, placed emphasis on the accessible environment.

The CCS Policy team continues to advocate for broad social change ... this ... has resulted in successful awareness campaigns, including 'Let's Get in Early' and policy work around mobility parking, public transport, and the 'Moving around Communities' project. The CCS policy team continues to lobby for fully inclusive

education for all disabled children and works closely with organisations such as IHC and DPA to further this objective ... The team is engaged with organisations such as Human Rights Commission, and the Ministries of Social Development, Health and Education. (NZCCS, Annual Report, 2005/ 2006)

Complementing these campaigns, which introduced NZCCS's work to the wider community, were training opportunities, provided to staff and governance members inside the organisation. Workshops on social service development and community involvement for staff and LAC chairs throughout the organisation were conducted by Michael Kendrick in 2001. He introduced the concept of Social Role Valorisation (SRV, discussed in Chapter Four) to management and governance.

CCS again provided a range of training opportunities relevant to improving services for disabled people. We ran a highly successful national workshop that visited 17 venues around the country and attracted more than 450 participants, from both inside and outside the organisation. (NZCCS, Annual Report 2001)

The social change component of NZCCS's work became more prominent in the mid 2000s. A major new initiative introduced the idea of social enterprise or business with a social focus into CCSDA's programme. In 2005 New Zealand CCS launched 'Lifetime Design', a company providing building standards (Lifemark) for accessible housing ("Lifetime Design"). The intent was to substantially increase the accessible housing stock in Aotearoa New Zealand and create independent income for CCSDA by starting a successful business. Success has been achieved by selling the Lifemark standard to rest home developers, by increasing acceptance of the need for accessible housing in the building sector and by receiving funding from Housing New Zealand to advance development of accessible social housing.

Another important component of CCSDA's work complementing the social change agenda was the lobbying of government agencies to achieve inclusive policy development. The policy team at National Office consisted of highly skilled disabled people from 2006 including Paul Gibson, National Policy and Strategy Manager; Ruth Jones, Tumu Whakarae, the National Manager Maori Policy and Strategy (established in 2006); Michelle Hill, highly experienced Information Manager; Peter Wilson, National Development Manager; Ali Bradshaw, National Fundraising Advisor and Matt Frost, Policy & Information Researcher. The direct involvement of so many skilled disabled people with links to the disability community and disability rights advocates themselves resulted in cooperation with People First, DPA and other disability rights organisations and led to many successful submissions regarding government policy and legislation.

The CCSDA policy team registered many lobbying successes such as work on the submission to the Parliamentary Justice and Electoral Select Committee on the principles of the Treaty of Waitangi Deletion Bill in October 2006¹⁹. CCSDA prepared two major submissions for the Parliamentary Social Services Committee Inquiry into the quality and care of services provision for disabled people in 2006 and 2007 with many suggestions on how services might be improved (NZCCS Submissions, August 2006; Version 2, May 2007). The policy team worked on the Repeal of the Disabled Persons Employment Promotion Act (2007), promoted the increase in fines for mobility parking misuse from \$40 to \$150 (2008) and developed the Journey to Work (2009) in conjunction with Workbridge, the successor of the Rehabilitation League. Submissions and advisory work by the policy team also extended to wording for the UN Convention on the Rights of Persons with Disabilities (2006). CCSDA policy team members developed submissions to the UN Convention in conjunction with DPA (Wendi Wicks, Policy Analyst) in 2003. Work continued with a submission to the Office for Disability Issues (ODI) on the Ratification of UN

¹⁹ The proposed law suggested to eradicate references to the Treaty of Waitangi from all new legislation.

Convention in April 2008 and with comments on the UN Review of NZ Human Rights situation in May 2009.

Another important development in the late 2000s was the change of name to CCS Disability Action (CCSDA) Including all People.

In July 2007 we changed our name to CCS Disability Action. This has had a profound effect on the way that people look, interact and work with us ... this past year we really set ourselves the challenge of living up to our new name ... To be able to show this we have consciously moved away from the traditional models that charities have long operated under ... You won't see people shaking buckets on the streets during our awareness week. (CCSDA, Annual Report, 2007/2008)

The new by-line 'Including all People' reiterated the expansion of people covered by the work of CCSDA. Although this change has happened almost a decade ago clarification and reinforcement was thought to be advisable:

Our new by-line 'including all people' has been keeping us on our toes. It is a reminder that our work should be for the benefit of the whole society, not just children, not just physically disabled people, but everyone in New Zealand ... even if we do not have the specific knowhow for them we can still make things easier by putting them in touch with the people that do. (CCSDA, Annual Report, 2007/ 2008)

A kaumatua from the Bay of Plenty donated a Maori proverb to CCS Disability Action to express the dictum of 'Including all People' in Maori. 'Te Hunga Haua Mauri Mo Nga Tangata Katoa' - expressing the belief that all people have mauri or life force and equal value and this was widely used in all CCSDA documentation and waiata since 2007.

The other element of our new branding has been the gift of our Maori foundation statement 'Te Hunga Haua Mauri mo nga Tangata Katoa'. In essence it celebrates the unique life force and energy that all people possess regardless of colour, creed or ability. We have been surprised and inspired by the number of conversations that this statement has influenced. (CCSDA, Annual Report, 2007/2008)

CCS Disability Action's strategic priorities from 2009 highlighted the vision of 'Including all People':

CCS Disability Action has a vision that every disabled person will be included in the life of their family and community. To achieve our vision we are taking action to make Aotearoa New Zealand a society where everyone plays their part to include all people - family members, friends, hapu, iwi, educators, health workers, business people, employers, councils, government, community agencies and the public. (CCS Disability Action, Strategic Priorities, 2009 - 2014)

In summarising it becomes clear that CCSDA had established close links with DPA and other self-advocacy bodies like People First since the late 1990s and connected with them as equal partners in contrast to previous relationships in the 1980s. CCSDA began to sponsor and support submissions to lobby government on behalf of disabled people. When Paul Gibson, a former DPA President, co-led the CCSDA policy team as Policy Manager from 2002 (part time) to 2009 with Ruth Jones, they recruited other DPA members to the policy team.

Major influence on policy by disabled people as the minority group most affected by the policy coincided with the social development approach's goal of including affected groups in policy development and at the same time met the goal of the DRM's 'Nothing about us without us' (Charlton, 1998).

The other component of the data for this research, the interviews with key players, is presented next. The participants are introduced and oral histories of participants illustrate the changing approaches from the early years of the New Zealand Crippled Children Society (1935), to NZCCS (1989) and CCSDA (2007), highlighting the close involvement of disabled people in the last 11 years.

Chapter Six: Oral histories. Interviews with key players

The interviews with key players in the New Zealand Crippled Children Society, NZCCS and CCS Disability Action contribute interesting insights into the social history of the organisation. The voice of early members of the New Zealand Crippled Children Society, interviews with people who identify as disabled people and professionals working in the fields of social work and social policy provide a wide range of viewpoints about the social history of CCSDA at different times of its history. Research participants are introduced in Figure 1 on page 32 detailing their time of and reasons for involvement and other relevant facts. The themes emerging from the interviews will show links to the documentary data and will reappear in the analysis chapter.

Interview questions

The oral history data are presented in the order the questions were asked and participants are named at the beginning of each response. Some questions were not answered by all interviewees. The interviews were conducted in a semi-structured way and personal comments of both the participants and the interviewer as well as observations about the New Zealand Crippled Children Society and CCSDA over the decades were included.

The interviews started with the question about personal connections to CCSDA followed by the question about services. This leads on to the question about principles at the time of involvement and to more strategic questions about societal treatment of disabled people and bicultural strategies concluding with questions about the future of CCSDA and general comments.

QUESTION 1: PERSONAL

First involvement

When was your first involvement in CCS Disability Action, what kind of connection and why? When was your involvement? Why did you get involved?

Lady Joan Gillies

Lady Gillies responded, saying that she was the second spouse of Sir Alexander Gillies (1891-1982)²⁰, the orthopaedic surgeon and Rotary member who initiated the foundation of the New Zealand Crippled Children Society. She became very familiar with the history of the New Zealand Crippled Children Society.

My husband and his late wife, a Canadian barrister, used to take children into their home in Wadestown before operations because they came from out of town and could not afford to stay in a hotel.
(Lady Gillies)

Lady Gillies remembers her husband's stories about the foundation of the Crippled Children Society with the help of Rotary especially the Wellington Club and the assistance of friends.

My husband mentioned that it was fortunate as Lord Nuffield, John Morris, founder of the John Morris bicycle business later car business namely the Morris Minor motor garage, was in the country²¹ and gave money to Rotary for crippled children. (Lady Gillies)

Lady Gillies explained the connection between Lord Nuffield and Charles Norwood:

²⁰ Sir Alexander Gillies was a friend of Lady Gillies' father and family. They were married in the early 1970s commencing a 40 year involvement by Lady Gillies.

²¹ At the time when the Society was founded in February 1935

Charles Norwood had the Morris Garage called the Dominion Motors Ltd. on Courtenay Place in Wellington and was acting as an agent for Morris cars. He later became the president of the New Zealand Crippled Children Society.²² (Lady Gillies)

Lady Gillies described the motivation of her late husband for the establishment of the New Zealand Crippled Children Society, it was the “sorrow to have children becoming disabled, that set him off” (Lady Gillies). Adding to the success of the Society were the international connections forged by Sir Alexander Gillies in the early years of his career according to Lady Gillies.

My husband worked for a man called the Father of orthopaedic surgery, Sir Robert Jones. He worked with him in Liverpool at his surgery in Rodney Street and at the hospital, the ‘Sir Robert Jones and Dame Agnes Hunt Orthopaedic Hospital’ in Shropshire which was established in the home of Dame Agnes Hunt who was disabled ... My husband has been to the Mayo clinic in Rochester, Minnesota in the USA. Later my husband was appointed as the senior orthopaedic surgeon at the Wellington Hospital. (Lady Gillies)

Today, Lady Gillies continues her involvement with CCSDA as an Honorary Member of the national society and as patron of the Wellington branch.

Tom and Marie Johnson

Tom and Marie Johnson were involved as accountants of the Hawke’s Bay branch from 1957 to the 1970s. Tom was the accountant of the Napier

²² Charles Norwood was a former Mayor of Wellington and Founder of the Free Ambulance service. According to Lady Gillies he was born in Australia, had a goatee and liked his cigar.

Education Board, the secretary of Heritage²³ and the treasurer of the local Rotary club.

Tom's skills were sought by Mrs Kent-Johnston [branch President], Tom was an accountant and known as being reliable ... We were in our mid-thirties and I am an accountant²⁴ too and we thought we could share the job. (Marie Johnson)

The question why they wanted to be involved was answered by Marie, who explained:

We were asked to and we were happy to do it, we didn't seek it. We had four very healthy children, haven't had our fifth yet. We had a good run, we thought we can do this ... we couldn't believe how it must be when you experience it [impairment]. (Marie Johnson)

When Mr. Johnson retired as an accountant, the involvement with the New Zealand Crippled Children Society ceased.

Ruth Jones

Ruth's first involvement with the New Zealand Crippled Children Society was as a preschooler in 1969.

I was referred to a visiting physiotherapist, and Miss Hartridge, she didn't have a first name, she started seeing me when I was two in 1969. She referred us to the New Zealand Crippled Children Society. (Ruth Jones)

²³ Heritage, a charitable organisation founded after the second World War to help families of soldiers who didn't come back. It was supported by local Napier MP Walter Nash.

²⁴ Marie's accountancy qualification was very unusual for the time, few women completed a university qualification. She had studied in Wellington, but then got married and didn't practise her profession.

Both Ruth and her sister were of Maori descent and were adopted by a Pakeha family²⁵. Her mother used social work support from the New Zealand Crippled Children Society to chat with someone, but she didn't want any connection to other families, camps and other segregated activities for Ruth. The New Zealand Crippled Children Society provided practical support for Ruth's mother.

My father died when I was six, Crippled Children Society sent a food hamper, they provided very much practical support. When I was in plaster they got us ramps and provided transport. From the age of 11 physiotherapy was provided through the hospital. (Ruth Jones)

Her mother's philosophical beliefs were based on a desire to achieve mainstreaming in all aspects of life and she made strategic decisions based on these beliefs including to enroll Ruth in a regular school. Ruth understood that the Society had initiated for her to go to a school for physically disabled. "Not so much because of principles just because it was the norm in those days and they were assuming that's where you go although I was assessed as being ahead of my peers" (Ruth Jones).

There was an assumption that services were required for life. Ruth de-registered from the New Zealand Crippled Children Society at the age of 18 in 1985; this was regarded as very unusual and Ruth understood that it had never been done before. It was Ruth's personal preference not to be a client when she worked for the New Zealand Crippled Children Society, NZCCS and CCSDA in various roles in the 1990s and 2000s.

I didn't want to be a consumer and staff in the organisation. There were amazing social workers in CCS in the 1980s, good practitioners with innovative philosophy of empowerment for

²⁵ Some young Maori mothers had their children away from their families to get their babies adopted by Pakeha families because of better social circumstances, to keep the birth a secret or to avoid adoption inside the Maori whanau especially when there was mixed parentage.

disabled people in contrast to the quite conservative approach of CCS. Maori was spoken and disability rights from a social worker's perspective were at the centre but without naming them. (Ruth Jones)

After a break Ruth joined the staff at New Zealand CCS in Christchurch as a social worker in 1993. "The division between staff and consumers was strict, the door between staff and consumers was locked, with the accessible toilets on the other side creating a problem for me" (Ruth Jones).

It was unusual to employ disabled people because the organisation was quite conservative according to Ruth; however individuals were innovative, employing Ruth without a driver's licence and enabling her to go to a Maori staff hui in 1993. Ruth worked as a social worker in the family support team until 1999. Working in the neonatal field with young mums she used to play down her disability.

You were running the gauntlet as a social worker, we did some innovative stuff. Here were older workers who were waiting for me to fall. People wouldn't recognise it as running the gauntlet, it was under the radar. We were very unusual, I was a bit of a 'golden girl' because I was disabled and Maori ... I could play being able-bodied, I could play the game, I could have a drink. (Ruth Jones)

When Ruth returned to NZCCS in Christchurch as the service manager in 2001 she was the first disabled person in this position in the entire country. She was second in command to the regional manager.

I was service manager until 2004 - now acknowledging my disability openly - and I started employing many disabled people. It was a bit of both; they were employed because they were disabled people but also because of their skills. I didn't think about the impact on staff.

Workbridge provided job support. We employed one support worker who could support several disabled people and got a full time job out

of it. There were great learnings from employing disabled staff especially when disabled people didn't accept job support. It was no fault of the organisation, we didn't do things purposefully wrong, we just didn't know. (Ruth Jones)

Ruth Jones worked as the Tumu Whakarae, the Maori Policy and Strategy Manager at National Office from 2006 to the end of 2009.

Paul Gibson

Paul's involvement with the disability community began when he was diagnosed with an unusual eye condition which wasn't helped by glasses at the age of four and a half in 1966. As his sight deteriorated Homai School for the Blind was suggested to his parents but rejected in favour of the local primary school. The family lived in rural Taranaki, a long way from an airport let alone a school in Auckland.

From a young age I was conscious about a concept of disability, I developed in my own mind what I might call now an analysis of disability and the communality across impairment groups - I didn't language it like that as I was 7 years old. But I was aware of another girl in the district ... who didn't go to our school, she went to an institution. I was conscious this could have been me, that I was lucky that I was where I was rather than going away somewhere else. (Paul Gibson)

Paul was aware of the different disability organisations like NZ Crippled Children Society as a high profile organisation in parallel with the Royal New Zealand Foundation of the Blind (RNZFB). Paul did some contract work for CCSDA in the late 1990s and started as Policy Manager part time in 2002 (2006 full-time) until 2009.

Maurice Priestley

Maurice was born in Gisborne in 1951 and contracted polio at the age of 21 months in November 1953 in one of the last polio epidemics. During his two years in hospital in Gisborne the New Zealand Crippled Children Society fieldworker Mrs. Dickson visited regularly and the society was supportive behind the scenes.

I started doing correspondence school at home and went to the local primary school after 2 years. I was wearing callipers and crutches then and to get to school - I didn't have a wheelchair - we were using a pram, my brother used to push me to school. The New Zealand Crippled Children Society coordinated and paid the taxi to the hospital for physiotherapy. (Maurice Priestley)

The New Zealand Crippled Children Society paid for the taxis to secondary school (until Maurice was 16 which was the cut off point for services from the New Zealand Crippled Children Society in 1967). In the early years Maurice remembered support for families and making connections to other disabled children in the same town. The lavish Christmas parties in a grand old place with Father Christmas on a fire engine and the presents for the 'CCS kids' are a fond childhood memory.

In 1961 when Maurice was 10 years old, the New Zealand Crippled Children Society did major fundraising to enable Maurice to have spinal fusion surgery in Edinburgh, Scotland.

The whole sending me off to Britain was planned for quite a while. My orthopaedic surgeon kept in touch internationally, there was groundbreaking work going on in respect of scoliosis. They figured I had to grow to a certain age before they would fuse the spine so that it didn't get any worse. (Maurice Priestley)

One and a half years after his return from Scotland he was sent to Middlemore hospital to have all previous operations repeated and Maurice spent 12 months in Auckland with periods at the Wilson Home to recuperate from the operations.

Why? Back to the conspiracy theory, what's a good way of teaching young local orthopaedic surgeons? That's just my theory, I have nothing to go on. With all these hospital experiences there was a daily round, there were these indignities of being photographed naked. I just thought: here we go again, this is just what happens. (Maurice Priestley)

Maurice reconnected with NZCCS in the late 1980s when the first consumer advisory groups were established, he was on the National Board from 1998 to 2002 and is now involved in local governance in Wellington.

Viv Maidaborn

Viv's first connection with the New Zealand Crippled Children Society was in 1970 as a child when her mother worked as a cook at the Wilson Home in Auckland and on Christmas her family hosted 'crippled children' who had no family.

In those days the Crippled Children Society was a much bigger presence at the Wilson Home. The principles of the New Zealand Crippled Children Society's were clearly charitable. Here was the cook in the kitchen taking home kids for Christmas because there was nowhere else to go. (Viv Maidaborn)

Messages regarding 'crippled children' her mother conveyed were "be nice, poor child, better than" but also the intention to be charitable and generous. Christmas parties were huge organised events for resident children and staff and their families.

Viv was the manager at the Wilson Home in Auckland in the 1980s and CCSDA's CEO from 2004 to 2011.

Services

Which services were available when you were involved?

The participants comment on different eras of service delivery. Lady Gillies refers to services in the first decade of the NZ Crippled Children Society whilst Tom and Marie Johnson contribution is valuable because they report services in a local branch from the late 1950s to the 1970s. Maurice Priestley experienced services from a local branch and services funded by the national Society in the 1960s. Viv Maidaborn's observations relate to services in the 1990s. Paul Gibson and Ruth Jones concentrated on strategic considerations rather than answering specific questions about services.

Themes such as the emphasis on medical treatment, the acceptance of residential services and the language of impairment and disability at the time become apparent.

Lady Gillies

Lady Gillies described the services offered by the New Zealand Crippled Children Society from the foundation in 1935 as transport of crippled children to hospital appointments, physiotherapy and swimming with "transport provided by volunteers just like meals on wheels now" (Lady Gillies).

Field officers linked crippled children and their families to the Society's services such as travelling clinics.

My husband travelled to Nelson, Wanganui and Dannevirke and held travelling clinics and some children returned for follow-up treatment in Wellington. He did the work by himself. (Lady Gillies)

Marie and Tom Johnson

Tom and Marie Johnson remembered that the field officer made home contact and field officers were heavily involved in clinics:

There was not much contact with schools more with hospitals. It was really helping with the medical side and with shoes for the club feet. (Marie Johnson)

As the accountants of the branch Tom and Marie arranged consultations for children with cleft palate in Wellington with plastic surgeons²⁶ and paid for transport and accommodation from branch funds.

We did the arranging for Wellington visits for the cleft palate people. There was a husband and wife team, they were wonderful people; they were plastic surgeons and they did great work with the cleft palate people; we arranged transport to go to Wellington. (Tom Johnson)

Children with club feet were treated in Hawke's Bay. Clinics were based in the hospital on Napier hill and Geoff Taine²⁷ was the orthopaedic surgeon there. "We helped with transport to the clinics and there were many Maori children with club feet" (Marie Johnson).

In the 1950s until the 1970s when Tom and Marie were involved, assistance to get medical attention and employment as well as the organisation of holiday camps were priorities.

We used to have an annual holiday camp on the Alexander family farm. We ran the camp and stayed with the whole family and

²⁶ Dr. H. Pickerill and his wife had offered their services as plastic surgeons to the Society (Frost, 1960, p. 50).

²⁷ A Crippled Children Society respite home in Hawke's Bay in the 1980s was named after him (Taine house).

everybody helped ... and we had a nurse ... We had the use of their shearers' quarters and it was a success. The local people rallied around and organised picnics. (Marie Johnson)

According to Marie and Tom Johnson no Maori families were involved: "I think they didn't want to be involved, I hope it wasn't the other way around that field officers didn't want them" (Marie Johnson).

When the local holiday camps finished, children from Hawke's Bay were included in Wairarapa camps with transport provided by the society. Other services Tom and Marie supported were sending children to Pukeora and the Wilson Home:

Pukeora was available; Pukeora started as a TB sanatorium in the 1930s and 1940s. In some way there was an involvement we took people there or visited them. And the Wilson Home, we had people go up to there. (Tom Johnson)

As volunteers Tom and Marie Johnson helped with transport to clinics, to the swimming pool and to pottery classes. "Gary, he was a Spina Bifida; a local firm, Morrison Mirrors, was very good and employed him, we did a lot of transport with him" (Marie Johnson).

Maurice Priestley

Maurice Priestley experienced services provided by the New Zealand Crippled Children Society first hand as a child when he was sent to Scotland for operations in May 1961. Maurice and his mother left Wellington on the Rangitane for the six week journey and on arrival in Southampton, "the Maori boy from the colonies"²⁸ was greeted by the press and hordes of

²⁸ Maurice's father was of Ngati Porou descent.

photographers followed him on his way to Edinburgh.²⁹ A series of operations fusing his spine were performed in two stages followed by long periods in a cast from head to toe convalescing in a rest home full of old men for most of the year.

The surgeons decided they had to straighten my bent right foot and they took a muscle from the other side. And they wanted to make the leg longer to make it look normal. They didn't ask me and I don't know what sort of consent they had from my Mum. They also operated on the hip because it had dislocated and they had to wait until I was out of plaster. I wasn't the only one from New Zealand who went over there. (Maurice Priestley)

Schooling at the hospital brought Maurice in contact with other disabled children. For the first time in his life he experienced bullying not because of his disability but because he was an indigenous boy from the colonies. "What they were teasing me about was: Maoris run around naked and eat people. I found much more discrimination there than at home" (Maurice Priestley). Some procedures took longer than expected and Maurice and his mother lost the berth on the ship booked for 12 months after their arrival. "We went to the New Zealand Embassy for help but all they were interested in were getting immigrants" (Maurice Priestley). The family asked the New Zealand Crippled Children Society for help and they raised the funds for the airfare back to New Zealand.³⁰

Viv Maidaborn

Viv Maidaborn commented on the difference between health services and disability related services delivered at the Wilson Home. Viv experienced

²⁹ The train journey to Edinburgh ended at 11 o'clock at night and he was admitted to hospital on the night of arrival and separated from his mother. The rest of his family, his father and two siblings had to cope for a whole year by themselves in Gisborne. His mother who was living with acquaintances in Edinburgh had to find work to support herself.

³⁰ "A real adventure for a boy flying on a Boeing 707, one of the first jets which didn't even get to New Zealand. We got a flight with Qantas to New York and San Francisco, and a few hours sleep in Fiji. From there on a Teal Turboprop to Auckland and a DC 3 to Gisborne" (Maurice Priestley).

the split when her son was born with a heart condition in 1992 causing mobility and growth problems.

What I learned was that a completely ridiculous split between personal health care and disability support existed what I learned is that there is a lot more practical problem solving that goes on with the disability support mindset than with the personal health mindset. (Viv Maidaborn)

The analysis will return to themes such as medicalisation of disability with the power of decision making removed from disabled people who are given a passive role, the preference for safe residential services and the language of the earlier periods. These findings reflect the popular perception of impairment and disability of the time.

Principles

What principles do you think CCS Disability Action had in the days when you first got involved? Do you think the vision has changed and how? Do you agree with the direction the organisation has chosen?

Support for disabled people is highlighted as the major principle of CCSDA. Paul Gibson and Maurice Priestley did not comment here, but reflect on CCSDA's vision in their general comments.

Lady Gillies

Lady Gillies welcomed the extension of the client base: "These people, Spina Bifida, Spastics, intellectually handicapped patients are all accepted. This is a good thing especially as there are many accidents in the home" (Lady Gillies). She also acknowledged a definite change of the vision: "The vision has changed because lifestyle has changed, it's not the cure of illnesses just getting treatment" (Lady Gillies). Asked if she agreed with the new direction, Lady Gillies commented that: "there is no

alternative as there is no raging disease; one has to look at patients with other problems, the problem with polio is over” (Lady Gillies).

Tom and Marie Johnson

Commenting on the principles of the New Zealand Crippled Children Society at the time of their involvement: “Didn’t have any, it was just a case of looking after crippled children and tracking them down ... I don’t remember a connection with schools, field officer had no connection with education” (Marie Johnson).

Tom and Marie Johnson added that residential care and the safety of institutionalisation was regarded as the best option for crippled children and their development and for their families.

Ruth Jones described the principles of the New Zealand Crippled Children Society when she was first involved as wanting to help and providing support. Viv Maidaborn described the principles of the New Zealand Crippled Children Society as clearly charitable.

Themes such as a preference for residential services and language used in previous times will surface in the analysis again highlighting societal responses to impairment and disability at different times.

QUESTION 2: SOCIETAL TREATMENT OF DISABLED PEOPLE

How do you envisage inclusion of disabled people? What are the main features of inclusion into society? Has inclusion of this minority group been achieved and aided by the researched disability organisation?

Difficulties experienced with the inclusion of disabled people and differences in acceptance between ‘crippled children’ and children with learning difficulties in the early years appear in responses of participants. The theme of human diversity and the need for breaking the poverty cycle

are introduced by other participants as tools of inclusion with emphasis on the contribution by disabled people to society.

Lady Gillies

Lady Gillies described wheelchair users as:

Difficult to include. They need wider doorways and people in wheelchairs have problems in moving around, with steps and kerbs in the way ... The involvement of disabled people should happen through the field officers who go out and contact people. People have access to branches. (Lady Gillies)

Lady Gillies remarked on the improvements in including disabled people into communities because “years ago people were hidden in back rooms, families were worried about the reaction if they had a child that was unusual looking” (Lady Gillies).

Tom and Marie Johnson

There was always a “little problem of where the line was” (Marie Johnson).

We always felt that attitude towards crippled children was good, but IHC had a terrible time, they were not accepted. They were hidden, the public didn't mind the crippled child, but the IHC child was not for display. (Tom Johnson)

The lack of involvement of Maori families in the holiday camps was mentioned and as quoted before, Marie and Tom Johnson expressed the hope that this exclusion was not initiated by field officers.

Ruth Jones

Inclusion is interpreted by Ruth as “having the same opportunities, being safe and visible in a community and being able to contribute back into the community.” (Ruth Jones) Encouraging mainstream schooling and the visibility of disabled people in the job market is advancing inclusion into society according to Ruth.

Paul Gibson

Asked about his opinion on societal treatment of disabled people, Paul stated that:

Everybody should have the same opportunities with fun and friends, to live, love, learn; have a home, relationships and a job, enough income and a sense of being able to leaving the world behind better for us being there. These are simple things but also complicated and complex things which most people don't have to name. Disabled people and CCSDA as their support have to name the difference before you can include people and that creates tension ... Achieving inclusion is a continuing journey, individuals will always be excluded. However society is moving in the right direction towards diversity.
(Paul Gibson)

Maurice Priestley

Maurice suggested ways of monitoring inclusion by tools such as “the population health approach which uses social determinants such as housing, access to transport, education and human rights. This approach can include disability as part of human diversity” (Maurice Priestley).

Viv Maidaborn

Economic factors are identified by Viv as the main determinants of inclusion into the mainstream in the developed and increasingly developing world.

Being employed is often seen as the only successful way of inclusion, people's value is treated as an economic equation. To achieve true inclusion economic value judgement have to be replaced by the value of human life, love and relationships and the added value to the lives of the carers has to be acknowledged. (Viv Maidaborn)

Viv identified the creation of economic buffers as desirable to break the poverty cycle and make life fairer for disabled people not receiving ACC payments.

The Planned Lifetime Advocacy Network (PLAN) initiative in Canada³¹ is an overseas example of a way of breaking the poverty cycle and was mentioned by the four participants with recent involvement as a future model, aiding inclusion of disabled people into society.

Themes relating to the inclusion of disabled people into society include negative and positive perceptions of impairment and disability, awareness of a hierarchy of impairment, diversity and economic security as solutions to perceived problems of inclusion.

³¹ The Canadian Planned Lifetime Advocacy Network (PLAN) was founded in 1989; PLAN's mission "is to help families secure the future for their relative with a disability and to provide peace of mind" ("Plan for a Good Life"). The four core principles centre around caring relationships, contribution equals citizenship, independence from government funding and commitment to family direction. PLAN helps people to plan for a good life, supporting decision making by relatives with disabilities and achieving financial security which is interlinked with social well-being. Financial security information includes seminars about wills, trusts and estates and information about Canada's registered disability savings plan (RDSP). The RDSP is described as "a powerful long term savings tool ... with the money saved in an RDSP not impact[ing] disability benefits ... [and] the federal government will match funds with up to \$3 for each \$1 deposited" ("Plan for a Good Life").

Major achievements

Are you aware of major achievements by this organisation?

Are you aware of major achievements by this organisation regarding government policy development in Aotearoa New Zealand?

Looking at achievements of CCSDA, the themes emerging are distinctly different for both periods. For the early years connections to leaders and benefactors in communities as well as fundraising and building an infrastructure for services are highlighted. For the last 11 years influence on governmental policy by skilled disabled people is described as the most relevant to aid inclusion of disabled people into society. Maurice Priestley chose not to answer this question.

Lady Gillies

According to Lady Gillies involvement of many societal groups in the work of the Society was a great achievement: “Over 100 people attended AGMs for the Wellington branch in the 1970s, with doctors, dentists, government officials, Public Trust (bequest) and other trusts’ representatives in attendance” (Lady Gillies).

Tom and Marie Johnson

Marie and Tom Johnson mentioned the innovative filing system and the establishment of field officer positions as achievements. The building of a new headquarters for the branch and successful fundraising were also classified as achievements.

The local branch administration and management was guided by processes established in the bigger branches. An innovative filing system listing

disabilities as different categories was copied from Auckland Headquarters³².

Club feet, Spina Bifida, Cleft Palate, Cerebral Palsy, Hydrocephalus; Deafness and Blindness got a bit shady, there was contention about who was responsible and some fell through the gaps. We regarded the Auckland Headquarters as very efficient, we were in awe of it. We were impressed and guided by them. (Marie Johnson)

A great step forward occurred when “field officers were paid and they had a car” (Marie Johnson).

The new building in Napier was a great achievement for the local branch: “You can have that bit of land for a peppercorn rental. It was a Rotary negotiation, it was very exciting there was a creche and real headquarters ... A titled Lady from Central Hawke’s Bay came to open the building” (Tom Johnson).

Fundraising was regarded as another achievement “I don’t remember that anything was ever not done because there was not enough money” (Marie Johnson). Fundraising was aided by connections to the churches: “The person who co-opted me was associated with the Church of England” (Tom Johnson).

Ruth Jones

Ruth listed progress in reaching inclusion of disabled people as an achievement:

CCSDA is making progress in achieving inclusion, there is still a heart in CCSDA, visible particularly in the regions. Being a good

³² The Auckland Headquarters mentioned here was the National Centre at Mount Street provided for by the Dudley Trust for Crippled Children.

host, well-behaved and good hearted are valued components as well as being the best service provider CCSDA can be. (Ruth Jones)

Ruth mentioned innovative thinking and influence of CCSDA on government policy such as work on early support for families and the whanau ora concept. “It made a difference because we were out there, they saw Paul [Gibson] and Matt [Frost] and I around parliament ... I had a good relationship with Tariana [Turia]. That was the golden time” [2006-2009] (Ruth Jones). Ruth’s proudest moment regarding influence on government policy was the submission on retention of the Treaty of Waitangi in all legislation. Te Ururoa Flavell, a Maori Party Member of Parliament, quoted the combined submission by People First, DPA and CCSDA in parliament.

Paul Gibson

Major achievements by CCSDA regarding service development and government policy were highlighted by Paul and include:

A range of things such as mobility parking and care and support in the home. In the 1970s and 1980s there was not much home support, CCS was one of the first to introduce this, Bill Wrightson had some involvement ... More recently the work on the LAC³³ [local area coordination] model, we did a lot to sell this to government. It has to be driven from the perspective of the disabled people and their families ... The LAC model will prove itself so that the NASC system has to dis-involve. (Paul Gibson)

Work on the New Zealand Disability Strategy (NZDS) and the UN Convention by the CCSDA policy team under Paul’s leadership was directly relating feedback from disabled people and families.

³³ The Australian local area coordination model not to be confused with Local Advisory Committees, also LAC.

Viv Maidaborn

Asked about achievements of CCSDA, Viv Maidaborn makes the point that, looking at the long term, CCSDA has aided inclusion of disabled people into society.

Initiatives in the last years introducing new ideas such as Supported Independent Living [SIL] and Local Area Coordination [LAC] are frustrated by government moves to take over without accepting partnership with the community sector to develop the thinking around these models. (Viv Maidaborn)

Viv pointed out that influence of CCSDA on government policy extends to submissions on national and international law and incorporates legislation and policy beyond just disability issues.

The repeal of the Employment Act and the introduction of sign language as a third language are examples from the last 10 years. Changes achieved in the Children's and Young Persons' Act and the Guardianship Act point to realisation by CCSDA that this kind of legislation is crucial in the fight against discrimination of disabled children. Advocacy in this field is extremely important because disabled children are an even more marginalised group than disabled adults. CCSDA over the last 5 years has achieved a reputation of being a service provider and a disability advocacy leader. (Viv Maidaborn)

The influence on government policy, even if not directly related to disability, is the prominent theme for later analysis. The varying perception of disability and impairment at different times of the history of CCSDA reappears as a theme.

Has the broadening of the client base been able to avoid discrimination on the lines of gender, race, age, sexuality, severity and kind of impairment and social standing?

Problems with the broadening of the client base are accepted by Paul Gibson and Viv Maidaborn. Lady Gillies, Tom and Marie Johnson did not answer this question because they were involved before the client base was broadened and Maurice Priestley and Ruth Jones wanted to concentrate on other questions.

Paul Gibson thought that the broadening of the client base:

Avoids discrimination, but it is based on what expertise staff have to deliver services ... there are some services CCS has very limited experience with such as services for blind and deaf people and even Maori. It depends on local staff and their expertise to make it work. It's good that there is a more diverse group receiving services. (Paul Gibson)

Viv Maidaborn

The broadening of the client base is an achievement but has not worked as a strategy against discrimination by itself according to Viv, CCSDA's spread of services depends on the level of resources. "Discrimination relating to race and social standing still occurs and practical implication such as living rurally and extra resources needed by people with very severe impairment stands in the way of equal service provision." (Viv Maidaborn)

The broader client base is regarded as positive by all respondents. Race and social standing are identified as factors which create multiple discrimination against disabled people which will be incorporated into the theme of perception of impairment and disability in society and into the bicultural perspective in the analysis.

Ownership

Has the ownership of the organisation changed? What powers do the owners of the organisation have over philosophy and policy development?

The next questions about the ownership of the organisation was not answered by Tom and Marie Johnson and Maurice Priestley, as they wanted to focus on other questions. The growth of the disabled voice in CCSDA and the connection to disabled people's organisations in Aotearoa New Zealand emerges as the most prominent theme.

Lady Gillies

“Ownership belongs to financial members and people who give money like Trusts but not service users. Parents apply to CCS for help to be given by field officers” (Lady Gillies).

Ruth Jones

Disabled people connected to CSSDA are clearly the owners but the organisation doesn't serve the owners well because it creates dependency in Ruth Jones' opinion:

Often disabled people stay passive service recipients until they are suddenly asked to become leaders. Disabled people involved with DPA or other disability rights organisations are more independent. Distance from CCSDA, like deregistering for a while might be a good strategy for young disabled people. Allowing yourself to make your own mistakes and finding your own path is encouraged by disability organisations but not by CCSDA. (Ruth Jones)

Paul Gibson

Beside the legal owners of CCSDA there are a range of moral owners according to Paul Gibson in particular service users and their families. Responsibility of the organisation includes all disabled people across the disability community and communities in general have moral ownership, but also the responsibility to increase awareness about disability in the community. Paul identified staff with direct involvement, dealing with the issues, as moral owners and the CEO is accountable to them.

Viv Maidaborn

Viv Maidaborn expressed the opinion that the ownership of CCSDA has changed considerably with many more disabled people on Local Advisory Committees (LACs).

Owners vote on constitutional changes and with the power of the constitution they have power over philosophy. The Board is responsible for policy development but LACs [local advisory committees] have influence through the regional representative on the Board. Strategic priorities are determined by a consultation process and have to be aligned to the constitution which is voted on by the owners. (Viv Maidaborn)

Ownership of the organisation changed during its 75 year history and the growth of the disabled voice links to the theme of the influence of the DRM.

DRM influence

Do you think that the Disability Rights Movement (DRM) had a significant influence on the organisation?

Lady Gillies and Tom and Marie Johnson did not respond to this question as they were not familiar with the topic. Maurice Priestley remarked on the

importance of the disabled voice in the general comments. The connection between the DRM and CCSDA is acknowledged by all other respondents and will reappear as a theme in the analysis.

Ruth Jones

According to Ruth Jones, young disabled people in Canterbury, some of them with high and complex needs living in institutions but connected to CCS through attendance of social groups, were staunch disability rights advocates in the late 1980s. Ruth remembered that they voiced their opinions forcefully, at some stage storming into a local CCS Board meeting in Christchurch protesting their exclusion. Their action was supported by social workers according to Ruth.

I remember my mother was on the disabled living centre committee, located in an old house funded by Telecom. In the mid 80s we did not articulate it, but we knew that integration was the way to go, a natural thing to us because of the upbringing in the mainstream. (Ruth Jones)

Disability rights and advocacy were connected during Ruth's involvement with CCSDA because of the linked whakapapa of DPA and CCSDA in the policy team. Ruth commented that CCSDA's kaupapa should be centred around service quality valuing partnership with disabled people's organisations.

DPA, People First, ABC and other disability rights organisations give CCSDA the mandate, CCSDA gives them the capacity by partnering with financial and networking support. A good example was the combined submission on the repeal of the DPEP Act by People First, DPA and CCSDA, who contributed the Maori connections and good relationships with the Maori Party to the partnership. (Ruth Jones)

Paul Gibson

Paul Gibson acknowledged a definite influence of the Disability Rights Movement although the name DRM has only recently been introduced.

“Some disabled people would say that CCSDA to some extent is aspiring to be part of the DRM, but is not living up to it ... I think CCSDA is part of it through research” (Paul Gibson).

You can make the most difference in a life of a disabled person when they are younger, build the person up, build the family up ... The push around disability rights has been for disabled adults. The conversations between disabled adults and parents and families ... [are important] to share their experience about the journey. Disabled adults put their skills into the policy debate with strong focus on disabled children in areas such as education. I don't see many other organisations concentrating on those areas, other organisations, who claim to have a disability rights perspective are not making a difference, where the biggest difference can be made. That is the strength of the CCS model, working across the ages. (Paul Gibson)

Viv Maidaborn

Viv acknowledged the influence of the DRM on CCSDA through involvement of Local Advisory Committees constituted of disabled people, who are often members of DPA. When Viv started as CEO in 2004:

CCSDA had a Maori staff caucus but no caucus for disabled staff which indicated that more thinking about indigenous rights than disability rights had happened. Key threads of disability rights in CCSDA are disability leadership and role modelling inclusion. There is great learning in seeing the positive outcome of disabled people performing effectively in support, coordinator or management roles. (Viv Maidaborn)

Viv observed that the awareness of the DRM originates from connections with other human rights movements leading to the acknowledgement of disabled people as another oppressed group in society. In the last two decades more disabled people identified as members of CCSDA and were connecting the DRM directly to CCSDA according to Viv.

The influence of the DRM is a major theme for the analysis; it extends to disabled adult leaders in CCSDA continuing as the champion for the rights of disabled children.

QUESTION 3: BICULTURAL PERSPECTIVE

Are you aware of a specifically Maori influence on the organisation?

What do you know about bicultural strategies in the organisation?

The questions relating to biculturalism and multiculturalism are not answered by Lady Gillies and Tom and Marie Johnson because they were not familiar with this topic. The development of bicultural strategies in CCSDA (see National Bicultural Strategy, p. 97) is one of the prominent themes in the analysis.

Ruth Jones

In the early 2000s the courageous thinking of Rob Williams as the CEO and Pat Hanley as the Policy Manager developed a bicultural perspective according to Ruth Jones.

Simon Tawha was appointed as the Tumu Whakarae or Kaitohutohu. Misunderstandings were obvious from the start, Maori and Pakeha talking past each other and expecting different outcomes. Maori coming from the Treaty background with protocol as an important component, NZCCS expecting a disability connection from a Maori perspective which turned out as unrealistic as the kaumatua involved

were not provided with information about impairment and disability.
(Ruth Jones)

The national platform emerged as another complication and the Board decided to dis-establish the two entities of the Maori structure and return to local Maori involvement in 2006. Ruth commented that some regions insisted on strict adherence to protocol, others have created strong regional Maori staff groups and incorporated advice from young disabled Maori people. “Kaumatua come out of the culture of the branch or region and the new approach with assistance from disabled Maori Board members increases involvement of young Maori on Local Advisory Committees”
(Ruth Jones).

In 2006 Ruth applied for the position of Tumu Whakarae, the Maori Policy Manager at the National Office and joined a policy team made up of skilled disabled people with strong connection to disability rights organisations like DPA, People First and ABC. Ruth was interviewed by a panel with two Maori representatives: Marion Wellington, a whakapapa expert from DPA and Monty Daniels who was the representative of Koeke Tamata on the National Board. Paul Gibson, the leader of the policy team and Viv Maidaborn, the CEO completed the panel.

After Ruth was appointed, the CEO Viv Maidaborn said:

We will not have a Powhiri but a sacred welcome, unfortunately my radar didn't go... At National Office, they didn't know what to do with disabled people. In the branches they are used to disabled people, in the National Office we had to build it from nothing. (Ruth Jones)

Ruth Jones recalled her struggle in her role as Maori Policy Manager to anchor the Maori foundation statement gifted by Kihi Ngatai as an important part of the new name in 2007 (see pp. 102-103). The statement is

now prominent in all CCSDA correspondence and according to Ruth often used at hui to establish the connection between Maori and disability rights perspectives.

Paul Gibson

Paul's personal involvement with Maori culture reaches back to his childhood:

Growing up in local Taranaki the place I was born in was called Kaupunga, the fern that thrives in the dark or literally translates as blindness. One of the local hapu is Ngati Haua, disabled people. I was a curious kid and had a Maori friend whose grandparents were kaumatua who told me Maori stories surrounding disability. They talk about: don't cross the river, meaning it is confidential from one iwi to the next. I was let in because I was a disabled kid, partially blind and had the lived experience as a seven year old kid but I am not a Maori myself. (Paul Gibson)

Paul has experienced "Maori being tense around CCSDA across the Treaty divide" (Paul Gibson) and not bringing much disabled voice to the table. There are still misunderstandings, leaving situations where Maori feel unsafe and not hosted well. Overall Paul thought that CCSDA had done "leading work around bicultural development" (Paul Gibson) but he suggested to try "a combined way of extracting the cultural thought across organisations" (Paul Gibson) to save Maori having to engage in multiple connections.

Maurice Priestley

Maurice confirmed that connections between Maori communities and the New Zealand Crippled Children Society developed early especially in areas with big Maori populations. Maori on the East Coast were part of organisation from the beginning but there was no bicultural aspect.

Although field officers established connections with Maori families and communities, Maori cultural aspects were not included “it was all done the Pakeha way” (Maurice Priestley).

Viv Maidaborn

The bicultural journey of NZCCS in the 1990s saw whanau support groups started as staff support groups with no separation between consumer and staff, regular hui helped the engagement process. “Problems arose as Maori kaumatua had not much connection to disability and whanau support group suffered from a lack of direction” (Viv Maidaborn).

A separate structure for Maori called Te Waka Whakapakiri was in place when Viv started as CEO in 2004.

Initially Maori staff from each region came to the hui to voice their opinion and kaumatua agreed, giving Maori staff strong influence on management decisions and an unfair advantage over other staff. Rob Williams [former CEO] and Lyall Thurston [former President] therefore created Pukenga Rangatira to separate kaumatua from staff according to the Carver Model theory introduced in the Millennium Charter. (Viv Maidaborn)

The analysis will include the bicultural development in CCSDA which often followed bicultural directives from the government including funding requirements and changes in Maori society such as the change from a rural to an urban population.

Biculturalism versus multiculturalism

Are you aware of the discussion regarding biculturalism versus multiculturalism?

Both biculturalism and multiculturalism are important components of CCSDA strategy and are developed in parallel often with bicultural achievements leading the way.

Ruth Jones

The question about the weighting of biculturalism and multiculturalism and about the prioritising of one over the other is answered by Ruth with the observation that both can go hand in hand if biculturalism is Treaty based and multiculturalism works from the cultural competency platform. As long as both are not mixed up and the indigenous culture is recognised, respect for all cultures can emerge. Ruth recently worked with refugees who understand the Treaty and value the recognition of the Maori culture in Aotearoa New Zealand.

Paul Gibson

Paul stated that CCSDA was doing some leading work around biculturalism and is applying what works well to other cultures.

Biculturalism and multiculturalism are not an either or as long as CCSDA acts Treaty compliant ... and models partnership across other cultures in similar ways. Strengthening the diverse thinking in families around disability rights is another way forward. Western culture highlights socio-economic barriers as a result of disability, in other cultures the problem might be the access to the spiritual field, relationship between tradition and thinking around disability. Many cultures have positive stories surrounding disability and it is helpful not to make too many assumptions. Staff and champions have to provide leadership and strategic direction in the cultural field interpreting deeper meaning, be aware of what's unsaid ... Not everyone has to know everything as long as they don't get in the way. Traditional thinking within cultures can be explained through stories, people with instinctive knowledge of culture can translate it for others. Cultural awareness has to be combined with time devoted to disability issues. (Paul Gibson)

Maurice Priestley

Looking at other cultures, Maurice commented that many cultures have different views about disability reaching from the disabled person being a seer or prophet to the view of the wrath of God or punishment for the sins of the fathers. In Nazi Germany disabled people were used for medical experiments and humanity has to be careful not to repeat mistakes of the past or forget history.³⁴

Viv Maidaborn

Bicultural and multicultural thinking in CCSDA has developed particularly over the last decade. The rights of Maori as tangata whenua and being aware of other cultures are both very different. “If equity is the goal it is not ethical to wait for biculturalism to be achieved before acting about multiculturalism but a particular relationship with Maori has to prevail” (Viv Maidaborn).

Bicultural development as Treaty based and multicultural development as cultural competency based will re-emerge as a theme in the analysis.

QUESTION 4: GENERAL QUESTIONS

Where do you think the organisation is heading over the next five years?

The future of CCSDA is discussed next with questions about social change complementing service provision and the concept of social entrepreneurship and social enterprise³⁵ introduced into the discourse. Lady Gillies and Maurice Priestley comment on the general direction of CCSDA but together with Tom and Marie Johnson do not answer any of the following questions

³⁴ Maurice expressed concern about court cases in Nelson and Christchurch recently regarding the killings of a disabled child and a disabled man respectively.

³⁵ Social entrepreneurship is interpreted as an undertaking which will change society whilst social enterprise means a business with a social benefit as one of the goals (see Viv Maidaborn’s interview, p. 141).

about the social change agenda and social entrepreneurship, because they did not feel qualified to discuss these topics.

The strengthening of the disability community with a stronger disabled voice in CCSDA and a change in the relationship to the State emerge as prominent themes.

Lady Gillies

Lady Gillies saw the New Zealand Crippled Children Society as a charity emphasising personal interest in crippled children and in other philanthropists involved. She described CCSDA as more corporate now.

Ruth Jones

Asked about the future of CCSDA in the next five years, Ruth expressed the hope that CCSDA would evolve as an organisation driven by disabled people and their families whanau and that members start discussing “who and what we are” getting away from talk about what we are not. She also hoped for a policy team initiating strong strategic thinking.

Paul Gibson

Paul was reflecting on the change in the service sector: the growth in the disability industry and the appearance of service providers without an advocacy role might open up a new niche combining service provision and a strong voice of disabled people. He does not propose an amalgamation with other organisations because of possible loss of identity and history. A mechanism has to be established for CCSDA staff to communicate problems, like people missing out on a good life, through strategic channels. The new framework around the UN Convention is important and emphasis has to be on children, making a difference as early in life as possible. It is crucial to have “disability leadership on governance level and in staff and

management” (Paul Gibson). The voice of disabled people has to be strengthened and CCSDA can cooperate with and provide resources to disabled people’s organisations as well as “increasing the pool of people with the skills over time” (Paul Gibson).

Maurice Priestley

Maurice enjoyed the ‘business as usual’ approach to disability brought in by the ADA (Americans with Disabilities Act) which made accessibility for all mandatory and wants CCSDA to move lobbying efforts in this direction.

Viv Maidaborn

Looking at the next five years Viv regards the current CCSDA governance review as critical. Members as owners have to drive it with the Board as a leader and managerial change has to grow out of it.

The perception of impairment and disability in society and the strengthening of the disabled voice in CCSDA and in society within the framework of the UN Convention are important themes for the analysis.

Do you think it is appropriate that a service provider practises advocacy and promotes social change?

Social change: Advocacy

Strong preference of the combination of service provision and advocacy is apparent in the answers of participants: The connection to the grass roots through service provision and the resulting first hand experience of everyday problems provides relevant knowledge for advocacy and policy development.

Ruth Jones

Advocacy and disability rights were connected as the whakapapa of Disabled Persons' Assembly (DPA) and CCS Disability Action (CCSDA) were linked during Ruth's involvement. CCSDA kaupapa should be centred around service quality valuing partnership with disabled people's organisations.

DPA, People First, ABC [Association of Blind Citizens] and deaf organisations give CCSDA the mandate, CCSDA gives them the capacity by partnering with financial and networking support. The reconnection with the 'grassroots' and where CCSDA came from is essential. (Ruth Jones)

Paul Gibson

Advocating for disabled people's rights and achieving social change were high on the agenda in the last two decades of CCSDA, often led by disabled people in the organisation, according to Paul.

Combining service provision with advocacy and social change is appropriate and the responsible thing to do as long as conflicts of interest are managed. An example of effective social change is PLAN in Canada with a strong connection to service provision. A social change agenda cannot be purely research focused, it needs to be connected to grass roots affected by services including the silent voice. (Paul Gibson)

Viv Maidaborn

It is essential for Viv Maidaborn to keep both roles as service providers and social change advocates.

Being a national organisation is an advantage allowing a picture across country and real people's stories can be applied to policy. CCSDA cannot stop advocacy as organisations providing just advocacy are missing in the New Zealand landscape and DRM leaders such as DPA, People First, ABC are not stepping up. (Viv Maidaborn)

Paul Gibson as Policy Manager advocated for growth of an asset base for disabled people: A CCSDA initiative of a tax rebated savings plan for parents of disabled people with contributions by the government suggested by Paul was unsuccessful when it was presented to the Labour-led government in the 2000s according to Viv Maidaborn.

The influence of the DRM and influence on government policy become apparent as prominent themes for the analysis.

Do you think it is desirable that this organisation extends its activities into social entrepreneurship?

Social enterprise and entrepreneurship

Involvement of disabled people in all new initiatives is an essential theme together with the desire to keep the core kaupapa of CCSDA at the forefront.

Ruth Jones

Ruth expressed the opinion that the social entrepreneurship pathway will work if it is driven by disabled people and their families like the PLAN project from Canada.

Paul Gibson

Social enterprise as an idea is valid as long as the Board ensures that the core kaupapa is not lost.

The strategy is more credible if it develops under the leadership of disabled people; examples in the past have ended in loss of control over assets. CCSDA and its subsidiary Lifetime Design have not invited disabled people, who could add credibility and reality. (Paul Gibson)

Paul prefers the NGO model rather than a private business model because NGOs have a greater accountability back to people they support. On the subject of moving away from government funding he suggests other ways of generating income such as fundraising and enterprise of some sort.

Viv Maidaborn

For Viv social entrepreneurship is crucial for fixing problems in society not just organising them.

A service provider responds to problems of the day, a social entrepreneur thinks about what's causing problems and how we could solve them. Social enterprise although a good initiative is not social entrepreneurship ... The way forward is determined by the decision if CCSDA wants to organise problems that exist or solve them. Pallotta (2008) argues that capitalists have set up charitable organisations to make them feel better about the money they make. Pallotta (2008) continues that, if non profits are close to solving a problem by thinking along social entrepreneurial lines, they are breaking the rules. (Viv Maidaborn)

The path of social entrepreneurship and/or social enterprise might be the future of CCSDA although it is not welcomed by everybody. The prominence of the disabled voice in all developments of CCSDA is a major theme for the analysis.

General comments

All participants contribute general comments, often reflecting on important developments for CCSDA in the future.

Lady Gillies

This research report will prove that the average person is more aware of the work of the organisation, the type of patient and the number of problems for a patient. I think it would be preferable if CCS Disability Action had more personal interest. It now works more like a corporation and has lost not exactly warmth, but has lost being prominent in the news, ahead of its time. (Lady Gillies)

Tom and Marie Johnson

“Hospital clinics and the support provided to attend them were the big thing in our time and the field officer was the lynch pin, the connection between the Society and families” (Marie Johnson).

Ruth Jones, Maurice Priestley, Paul Gibson

The evolution of disability leadership in governance, staff and management of CCSDA is a recurring theme supported by Ruth, Maurice and Paul and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) emerges as an important component of any future development.

A new framework has to be developed around the UN Convention including a refit of the NZDS. Focus on both children and adults has to remain and connections have to be established as early in life as possible. Increased collaboration with other service providers together with a prominent disabled voice is the way of the future. Sharing ideas and partnership with organisation like DPA and People First and using the increasing pool of skilled disabled people to step into roles. (Paul Gibson)

Viv Maidaborn reiterated her opinion that social entrepreneurship was the way of the future for CCSDA.

Summary of Findings

The welfare, cure and rehabilitation of the ‘crippled child’ was placed in the centre when Lady Gillies and Marie and Tom Johnson were involved with the New Zealand Crippled Children Society in the 1950s and 1970s. They have been able to communicate the underlying medical model thinking of their day, with emphasis on the personal tragedy of impairment, with the power of the medical profession and the passive role of the disabled person. In that time period, public attitudes demanded categorising and institutionalisation of disabled people. ‘Crippled children’ and their families were expected to be grateful and to accept decisions made by social work professionals funded by rich benefactors, helpful communities and church groups. Well-meaning benefactors strengthened connections with their peers and built networks with other professionals and wealthy philanthropists in Aotearoa New Zealand and overseas.

The contrast between the views of the participants, who were connected to the New Zealand Crippled Children Society, and those presented by the other interviewees - Ruth Jones, Maurice Priestley, Paul Gibson and Viv Maidaborn - is striking and the noticeable change in the thinking and language around impairment and disability based on the social model of

disability is one of the emerging themes. Societal treatment of disabled people and the fight for inclusion is at the forefront of the thinking and CCSDA is presented as a social change agent. The extension of quality service provision to advocacy and emphasis on directing government policy is connected by the participants to the influence of the Disability Rights Movement (DRM) and the bicultural and multicultural development of the organisation. Disabled people are welcomed as owners of CCSDA and the evolution of disability leadership in governance, staff and management of CCSDA is a recurring theme supported by Ruth, Maurice and Paul. The Treaty of Waitangi, the NZ Disability Strategy and the UN Convention on the Rights of Persons with Disabilities emerge as the core documents leading into the future of CCSDA.

Some key points identified include the change in the perception and treatment of impairment and disability in Aotearoa New Zealand including the language aspect. Changing roles of disabled people, the growth of the disabled voice and its importance for CCSDA is another key component. The bicultural approach as a uniquely Aotearoa New Zealand aspect and the expansion of the thinking in CCSDA to multiculturalism manifests as another theme. The influence of the Disability Rights Movement is undeniable and closely connected to the representation of the disabled voice in the middle management of CCSDA from the 1970s. The influence of government policy and societal developments on CCSDA and the changing relationship between non profit organisation and the State complete the collection of themes used in the analysis.

The next chapter begins with a look at themes emerging from documents and interviews and leads to the analysis of data and findings. The analysis is guided by the social history methodology chosen for this thesis.

Chapter Seven: Analysis

The analysis is based on social history methodology (Hall 2007, 1999; Lloyd, 1986; Tilly, 1981; Trevelyan, 1942). Social history explores larger structures and individual people's experience with emphasis on experiences of ordinary people. Retrospective elements of social history present views of the current situation which is controversial and looks at the origins. Prospective elements examine what could have happened and why it happened and not something else. Insider epistemology is used to heighten disability awareness and awareness of socially constructed realities. As this researcher has only a vicarious experience of disability, involvement of disabled people was crucial.

The New Zealand Crippled Children Society from 1935 into the 1970s is described by Sullivan (2001) as a "controlling hand in the velvet glove of paternalism, voluntarism and charity" (Sullivan, 2001, p. 114) but as Dalley and Tennant (2004) suggest, the historical circumstance has to be taken into account. From the 1980s to the 2000s the influence of the DRM becomes more prominent and starting in the 1990s, disabled people are encouraged to take ownership of CCSDA. The analysis will show clearly that societal trends have a major influence on CCSDA throughout its 75 year history relating to the

- Popular understanding of impairment and disability
- Bicultural composition of society in Aotearoa New Zealand
- The disability rights movement
- Government policy and the relationship between non profit organisations and the State.

These themes are relevant because they show links between CCSDA's historical development and societal trends in Aotearoa New Zealand. The cross pollination of strategic developments regarding disability and bicultural awareness and parallels in policy thinking are manifold.

Popular understanding of impairment and disability in society and in CCSDA

Tennant (2007) commented that the awareness of impairment and disability in society was temporarily altered after the First World War. “The welfare mix was formulated for three categories of disability: blind people, the war wounded, and ‘crippled children’ ” (Tennant, 2007, p. 100). Medical advances in the treatment of men wounded in the war advanced many disciplines particularly orthopaedic surgery.

Orthopaedic techniques developed in wartime emergency situations were likewise extended to the civilian population, heralding an era of surgical intervention in disability - a development that was later seen as having negative as well as positive consequences. (Tennant, 2007, p. 100)

Medicalising disability was a logical step as impairment was seen as a personal tragedy to be treated and hopefully cured. The New Zealand Crippled Children Society was founded in 1935 as a charity supported by a privileged class of rich and well educated benefactors with international connections. Medical treatment, cure and rehabilitation for the deserving disabled and helping ‘crippled children’ to become useful citizens not depending on handouts from the State were the aims of the Society.

Sullivan (2005) building on Foucault’s notion of ‘correct training’ wrote, “the end product of these regimes is a disciplined subject which is both efficient and productive” (Sullivan, 2005, p. 29). Sullivan (1996) described the categorisation of disabled people and the dominating power of medical professionals in Aotearoa New Zealand:

In Auckland, the Wilson Home for Crippled Children and, in Wanganui the Duncan Hospital for Neuromuscular Disease, were private, charitable spaces where young polio victims could be treated.

Thus, ‘the paralytic’, ‘the cripple’, ‘the deformed’ ... were increasingly subjected to the medical gaze, diagnosed with greater precision, sorted into various medical categories, and, for the sake of convenience, became known quite simply as *the disabled* [emphasis in original]. More importantly, disabled people became subject to the curative regimes of the hospital, and the medical profession, and disability became synonymous with pathology and disease requiring medical intervention. In short, disability had become medicalised. (Sullivan, 2005, p. 112)

The New Zealand Crippled Children Society subscribed to the perception of disability at the time and based its services on the medical model of disability. The clientele was restricted to “crippled children ... not being mentally deficient” (Carey, 1960, p. 20), an attractive group which easily achieved “public sympathies and political investment” (Tennant, 2007, p. 100) as confirmed in the interview with Tom and Marie Johnson (see p. 120). Sullivan (1996) criticised the Society for the reinforcement of negative perceptions of disability and for the use of degrading images for fundraising, questioning the value of a charity like the New Zealand Crippled Children Society:

The assistance was double edged. First, CCS operated from a highly medicalised account of disability and, second, it shamelessly promoted images of crippled, dependent child-waifs in annual appeals for charity donations ... A particular perception of disability, disabled people, appropriate behaviour toward them, and what to expect in return was, thus, generated by CCS as a survival technique for the organisation. It became the dominant perception, a perception upon which many other voluntary organisations for ‘the disabled’ were to trade. From this perspective, CCS was a central part of the carceral archipelago that was being assembled to control and regulate the physically anomalous body in New Zealand. (Sullivan, 1996, pp. 113-114)

It took many years before the approach of NZCCS, which in the light of the current thinking about disability came to be seen as patronising, but was in step with societal attitudes, changed. Skilled disabled people working in the organisation in the late 1960s, 1970s and 1980s were worn down by consistent paternalism. Russell Kerse, National Services Director from 1969, promoted barrier free access to the built environment, helped to achieve inclusion of Section 25 into the 1975 Disabled Persons Community Welfare Act, which regulates that all public premises are accessible for disabled people by the ‘accessible journey’ and initiated Operation Mobility in 1977 (Beatson, 2001). Kerse resigned in 1987 “wearied by what he regarded as the continuing paternalism of NZCCS back then, its excessive deference to medics, and its preference for custodianship over the encouragement of its clients” (Beatson, 2001, p. 32).

From the late 1980s NZCCS encouraged disabled people, who, following the market driven philosophy of the day they now called consumers, to participate as advisors and to attend conferences. Maurice Priestley was involved at an early stage and recorded the patronising treatment he experienced at a conference: “What are you doing here?” (Maurice Priestley). With the Millennium Charter and the move from local Boards to Local Advisory Committees (LAC) and Local Executive Committees (LEC), involvement of disabled people and their influence on philosophy and vision was anchored in the constitutions of the National Society and of the 16 branches as separate legal entities.

Changes in the perception of impairment and disability moving into 21st century in New Zealand society were inspired by the New Zealand Disability Strategy (NZDS, 2001) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). The social development approach, from 1999 to 2008 the foundation of social policy in Aotearoa New Zealand, encouraged the involvement of disabled people in disability policy development, honouring the DRM’s catchphrase ‘Nothing about us without us’. CCSDA followed governmental trends and involved

skilled disabled people in middle management nationally and regionally (Ruth Jones, Paul Gibson) and in local and national governance (Maurice Priestley).

An important part of social change is the enlightened use of a language around impairment and disability. The connection between language and labelling and the treatment and acceptance of disabled people in society cannot be overestimated (Wittgenstein, as cited in Silby, 1998).³⁶ Jaeger and Bowman (2005) highlight how the use of disabling terms creates devaluing perceptions of disabled people in society.

Use of phrases such as the impaired, the disabled, the handicapped, the blind, the deaf, the deaf and dumb, and the crippled tend to dehumanize and objectify people with disabilities and should be avoided. It is offensive to represent someone as his or her impairment. (Jaeger & Bowman, 2005, p. 115)

Words and language surrounding disability are full of insinuations and the language used by participants differentiates various historical times. Charlton (1998) identifies the DRM as one of society's groups fighting the negative perceptions.

For the last two decades people with disabilities have waged a political, policy, legal, academic, and philosophical struggle to make disability-related language neutral and more responsive to the changing political and cultural world. (Charlton, 1998, p. 67)

Although progress has been made regarding language surrounding disability, with derogatory terms erased from daily use, the language still contains terms such as 'invalid's benefit, needs assessment, suffering from disability, wheelchair bound and retarded' perpetuating the patronising attitude prevalent in society in Aotearoa New Zealand. There are positive

³⁶ See Chapter Three, pp. 41-42.

signs of change however: “The pity ethos surrounding ‘cripples’ which generated early disability groups has been replaced by a whole new vocabulary, expanded understanding of disability, and new service providers” (Tennant, 2007, p. 224).

More positive signs of change in how society talks and thinks about and treats disabled people in Aotearoa New Zealand, manifested in inclusive policy development over the last decade. The perception of impairment and disability has changed fundamentally in the last 75 years - from that of personal tragedy to social oppression - but there was another ingredient that has to be acknowledged. Maori as indigenous people of Aotearoa New Zealand play an important role in society and influenced CCSDA in many ways.

Bicultural composition of society in Aotearoa New Zealand

At the beginning of the 20th century Maori lived predominantly in rural areas³⁷ and first attempts of contact by Pakeha welfare agencies and charities such as the New Zealand Crippled Children Society were unsuccessful. “CCS was one of the first disability organisations to try to extend its outreach to Maori children”. (Tennant, 2007, p. 101)

Maori parents showed an understandable reluctance to send their children far away for treatment in alien institutions, and continued to rely on traditional methods of herbal healing ... district nurses were seen as the most appropriate agents of ‘peaceful penetration’ (Tennant, 2007, p.101).

Maori communities were suspicious about Pakeha organisations such as the New Zealand Crippled Children Society because Maori culture and language was largely ignored by the organisation and integration into Pakeha culture was required (Maurice Priestley). “CCS emphasised Maori

³⁷ “According to a 1936 estimate 91% of Maori lived in rural areas” (Keenan, 2004, p. 210).

gaining greater understanding of the society's work, rather than the society understanding Maori reluctance to use its services" (Tennant, 2007, p. 101).

From the 1960s most Maori attention was initially directed at economic and social indicators. These painted a bleak picture of the state of Maori communities, especially since the migrations from the 1940s into urban centres in search of work. (Keenan, 2004, p. 208)

Although the Social Security Act of 1938 had promised equal rights to all citizens, Maori rarely received full benefits.

Distinctions between deserving and undeserving have also been founded on race; this has meant that Maori who have claimed social security rights have been more likely than Pakeha to be subject to scorn, scrutiny and supervision ... The heroism of Maori in their voluntary participation in World War II made it impossible for government to continue the belittling of Maori benefits. (McClure, 2004, p. 145)

From the 1970s Maori groups began to challenge the New Zealand government about Maori rights enshrined in the Treaty of Waitangi. The Treaty of Waitangi (ToW) Act from 1975 created the Waitangi Tribunal "to hear claims from Maori and to investigate allegations of Treaty breaches ... since 1975" and the ToW Amendment Act 1985 extended "the scope of the Tribunal's investigations ... back to 1840". (Keenan, 2004, p. 211)

Maori activism did not only influence law making and social policy development but also the field of social work.

Two themes are clearly significant ... The first is the increasing articulation of Maori development models and ways of working with tangata whenua and respecting cultural matters. The second theme ... is tino rangatiratanga, Maori sovereignty. The rise of Maori activism

in the 1970s was and still is an important influence on social work education. (Nash, 1998, pp. 33-34)

The increased acceptance of cultural diversity in social work education and increased acknowledgment of Maori culture in governmental policy influenced the strategic thinking of the New Zealand Crippled Children Society. Wide consultation inside the Maori communities resulted in Puaote-ata-tu (1986), a report for the Department of Social Welfare “identifying institutional racism as endemic in the department and other spheres of government” (Tennant, 2007, p. 172). The report influenced government policy making and the formation of the 1989 Children, Young Persons and their Families Act which was:

One of the first pieces of social policy legislation to make specific reference to whanau, hapu and iwi; it also required attention to culturally appropriate service provision and Maori family arrangements, and provided for iwi to establish their own social services. (Tennant, 2007, p. 172)

The New Zealand Crippled Children Society had changed its name to NZCCS in 1989 and in the same year the Treaty of Waitangi was acknowledged as a core document of the organisation. Maori involvement was welcomed and actively supported and culturally appropriate service delivery became a strategic goal. Work on a Maori strategy in the following years led to the establishment of a parallel Maori structure for the organisation in 1998. The resulting two entities, Te Waka Whakapakiri (services, staff) and Pukenga Rangatira (governance) were ruled by tribes with well established iwi structures and disagreements about protocol soon dominated discussions. Hui and conferences highlighted conflict between Maori cultural proceedings and traditional and new conventions developed internally in NZCCS (Ruth Jones, Paul Gibson, Viv Maidaborn).

Consultation between the organisation and its Maori members resulted in the creation of Koeke Taumata, an advisory body with one kaumatua on the National Board. The same problems of conflicting protocols persisted and the problem was finally analysed as a lack of a combination of Maori and disabled people voices. Maori advisors had only represented the cultural component not the disability rights aspect.

In the mid 2000s Koeke Taumata with the kaumatua role on the National Board was dis-established and a return to local Maori involvement signalled. The Board actively recruited Maori Board members with a lived experience of disability and two new Board members were appointed. Strong Maori staff groups in some parts of the country monitor CCSDA's services to Maori especially in regions with a big Maori population such as Northland, Auckland, Waikato and the East Coast of the North Island.

There had been misunderstandings between Maori and the organisation throughout its history (Ruth Jones, Paul Gibson). The holistic Maori concept of disability with the elements of family, cultural heritage, identity and physical environment (Kingi & Bray, 2000) was interpreted as "deeply rooted indifference of many Maori to many deformities ... which Europeans looked upon with horror" (Tennant, 2007, p. 101).

Maori were coming from a Treaty background with protocol as an important component, CCSDA was expecting a disability connection from a Maori perspective which turned out as unrealistic as the kaumatua involved had limited connections to disability. The national platform was identified as another complication and the return to local involvement of kaumatua with disability connections emerged as the right solution.

At the same time the holistic Maori concept of disability was researched by CCSDA as a significant factor influencing attitudes towards disabled people. The spiritual element around health and disability in Maori thinking was accepted as an important component (Ruth Jones, Paul Gibson).

Another important influence on CCSDA is the strengthening disabled voice: first in conflict with the organisation, then pioneered from within by disability rights advocates from the 1970s to the 1990s and finally led by disabled leaders with strong connections to the Disability Rights Movement in Aotearoa New Zealand in the policy team in the 2000s.

The Disability Rights Movement

After the First World War at the beginning of the 20th century well educated people with acquired impairments lead self advocacy groups and refused to be patronised (Tennant, 2007). People with congenital impairments were under-represented and often had to overcome internalised Ableism to emancipate themselves and start speaking up (see Ruth Jones' interview, p. 109). "Internalized ableism means that to assimilate into the norm the referentially disabled individual is required to embrace, indeed to assume, an 'identity' other than one's own" (Campbell, 2008, p. 157). Many strands had to combine to create a strong disability rights voice in Aotearoa New Zealand.

International examples of disability rights activism inspired disabled people in Aotearoa New Zealand to join the fight for equal rights (Ruth Jones). The fight against institutionalism, the struggle for access to communities and for the right to represent themselves united disabled people with diverse impairments against patronising service providers, arrogant medical and social work professionals and unsympathetic government bureaucrats, and lead to an increased awareness of social injustice.

In the early decades of the 20th century, disabled people were thought of as residents of institutions or they were hidden away in family homes and residential homes run by churches or other charitable organisations as confirmed by Lady Gillies and Tom and Marie Johnson. Returning soldiers from the First World War with acquired impairments such as blindness or missing limbs and people affected by several polio epidemics in the early

20th century changed society's response. The Pensions for the Blind Act (1924) introduced benefits for blind people acknowledging the necessity for compensation by the state.

The war had created a new class of disabled people: adult men who were often well educated and who had previously been able-bodied. They had not grown up with disability and with the assumption of childlike dependency attached to those disabled from birth. The situation in which their disability occurred rendered them the responsibility of the nation. Their wounds were honourable scars signifying sacrifice for the nation, not signs of racial inferiority. (Tennant, 2007, p. 99)

The resulting hierarchy of impairments was confirmed with the Inquiry into Mental Defectives and Sexual Offenders in 1924, giving prominence to eugenics thinking in containment policies around people with intellectual impairments and mental health issues. 'Crippled children' and the principle of care gained prominence with the establishment of the New Zealand Crippled Children Society in 1935.

Policies of containment, compensation and care had the principle of segregation at their core and in the 1970s self advocacy groups of disabled people started to appear, fighting for inclusion into society. In 1978 the New Zealand Coordinating Council for the Disabled (NZCD) was formed and was soon:

At loggerheads with CCS and IHC who blocked their attempts to become the New Zealand representative on Rehabilitation International because they were 'too much influenced by consumer interests' (Georgeson, 2000, p. 56). This should have served as an early warning of the entrenched and hostile attitudes of traditional organisations towards their 'children' when they start talking and organizing for themselves. (Sullivan, 2001, p. 97)

The International Year of Disabled Persons (IYDP) in 1981 was eagerly anticipated as a stepping stone to inclusion by many disabled people but critics such as Russell Kerse, who identified as a disabled person himself, exposed another angle:

We were required to expose for IYDP promotion and media purposes what I considered to be the negative side and separateness of disability. The token representation of disability in a range of activities did little to advance a feeling of belonging and involvement. There was, rather, a sense of 'poor them' and 'aren't they wonderful'. There seemed to be an emphasis on doing things for disabled people rather than acknowledging of what they already did. A division of the world into 'them and us' may always have been a repressed community feeling, but I felt that through IYDP we granted licence for it to be expressed. Personally, I felt demeaned to a degree not experienced before. (Beatson, 2001, p. 30)

The feeling of licensed segregation, a realisation that disabled people were regarded as the 'Other' and the influence of international human rights movements inspired the move towards a disability rights movement in Aotearoa New Zealand, uniting people with sensory impairments, mobility issues and learning difficulties in a pan-disability group, the Disabled Persons Assembly (DPA) in 1983.

The small size of Aotearoa New Zealand as a country with the concentration of disability related groups and individuals resulted in a partnership approach by the DPA towards service providers and allies which at that time diluted the effectiveness of DPA as a disability rights advocate.

The 1980s and 1990s confronted the disability community with attacks on the welfare system, threatening disabled people with economic hardship. The 1993 Health and Disability Act paved the way to the re-medicalisation of disability repealing the 1975 DPCW Act. Disability rights organisations

and NZCCS fought both policy developments separately with the result of weakening the effectiveness of the response.

At the beginning of the new century disabled people's organisations released themselves from close ties to service provider organisations. The emancipation of DPA was confirmed in 2001 when corporate membership was abolished and only disabled people and families were granted full voting rights. People First separated from IHC in 2003 giving people with learning difficulties an independent voice. The emancipation of disabled people and their congregation in disabled people's rights groups enabled cooperation between these groups and CCSDA as equal partners. Disabled people's organisations gave CCSDA the mandate to engage with disability rights issues and CCSDA supported the groups with financial assistance and networking support (Ruth Jones).

The strength of CCSDA model is the fight for disabled children's rights by disabled adults and can be regarded as the perfect foundation for becoming a true advocacy agency and finding a niche in the disability sector according to Paul Gibson. The strong advocacy with and on behalf of disabled people, particularly disabled children, changed the organisation's perception in the disability community, albeit for only a short time in the mid and late 2000s according to Ruth Jones who described the time as the "golden time" because the CCSDA policy team was made up of skilled disabled people with strong connections to the disability community and the DRM.

Involvement of disabled people prominent in the disability community as staff members was a great tradition in CCSDA³⁸ (Paul Gibson, Ruth Jones). Their innovative ideas such as advances in accessibility through the accessible journey, mobility parking and total mobility and the concept of barrier free were developed from the late 1960s onwards. Other groundbreaking work was undertaken on new services such as Supported

³⁸ Russell Kerse, Bill Wrightson, Pat Hanley, Lorna Sullivan from the late 1960s to the early 2000s; Paul Gibson, Ruth Jones, Michelle Hill, Pete Wilson, Matt Frost and Ali Bradshaw in the 2000s.

Independent Living (SIL), an early realisation of the need of services in the home of the disabled person.

However disabled staff often felt patronised (see Kerse, p.158) and Ruth Jones described the need to act ‘non-disabled’ in her early years as a social worker in NZCCS (see p. 110) and the disability awareness work disabled staff had to do at the National Office when she started there in 2006 (see p. 133).

Carrying on the tradition of innovation led by disabled staff, service delivery models such as Local Area Coordination pioneered in Western Australia and Queensland were introduced to the New Zealand discourse by disabled people in the policy team of CCSDA in the mid 2000s (Ruth Jones, Paul Gibson). At the same time the Canadian Planned Lifetime Advocacy Network (PLAN) model (see p. 122) was studied by a CCSDA Board member who identifies as a disabled person and CCSDA managers to develop similar models in Aotearoa New Zealand, growing assets for disabled people and breaking the poverty cycle. PLAN lobbies for disability savings schemes and is active in the field of guardianship supporting people with learning difficulties and mental health issues. PLAN was cited as an example for future development by the four interviewees involved in CCSDA in the last decade (Ruth Jones, Maurice Priestley, Paul Gibson, Viv Maidaborn).

Policy development and government lobbying flourished under disabled leadership with a strong policy team at National Office in Wellington from 2004 to 2009³⁹. The strength of the CCSDA model was using a disability rights perspective developed by disabled adults and applying this perspective to the protection of the rights of disabled children. The close cooperation between CCSDA as an organisation with a social change and disability rights advocacy agenda and disabled people’s organisations

³⁹ This thesis only looks at the involvement of disabled people in the National Office, inclusion of disabled people as staff in branches lies outside the scope of this thesis.

benefited both parties especially as it was combined with quality service provision by CCSDA to keep direct connection with day to day problems of living with impairment and disability (Ruth Jones, Paul Gibson, Viv Maidaborn).

Government policy and the relationship between non profit organisations and the State

The foundation of the Crippled Children Society coincided with the election of the first Labour government in 1935 and the change of policy focus to more state interventionism. This resulted in the creation of the welfare state with the Social Security Act of 1938 and Belgrave (2004) reminds us that it is vital to understand that the family was at the centre of Labour's social policy not citizens' rights.

The stress on a middle-class, male-headed family and European values has led many commentators to denote the period [1930s] as conformist, patriarchal and assimilationist. While accepting the limited social compass of the key social policy goals of the period, this condemnation is justified, but only in retrospect. (Belgrave, 2004, p. 31)

The same criticism can be levelled at the New Zealand Crippled Children Society founded in 1935 but it is necessary to look at the Society in its historical context. In a mission statement in the Annual Report of 1938/1939 voluntary work and the Society's relationship with the State was described and the accusation of condescension was rejected.

From the point of view of the voluntary organisation there are those who protest that the voluntary organisation is out of place in work which is the duty of the State to undertake. To them the word 'voluntary', in such a connection suggests a condescending benevolence which is wholly distasteful ... It is the function and

privilege of the voluntary organisation to go ahead pioneering the unknown fields, testing and exploring in ways which the State controlled body hesitates and rightly so, to attempt (Annual Report 1938/1939).

The pioneering aspect in this Annual Report highlights the supplementary role of voluntary organisations. Tennant (2007) identified three functions of non profit organisations as complementary, supplementary or adversarial and stated that “the role of CCS was both supplementary and complementary to that of the state. It provided its own services to ‘crippled children’ ... while acting as a conduit to state medical services” (Tennant, 2007, p. 101). In recent years with social change firmly on the agenda, the policy team, made up of skilled disabled people, led CCSDA to assume an adversarial role by fighting governmental cuts in funding for disability services and by introducing innovative ways of thinking around disability into policy disputes.

Innovation was an important element of the organisation since its inception. The New Zealand Crippled Children Society “injects a new element into the story of welfare voluntarism: the international service club, in this case Rotary ... If Rotary oversaw the gestation and birth of CCS, philanthropists came forward to act as godparents” (Tennant, 2007, p. 100). The wealth of the new Society attracted the interest of state agencies such as health and education departments; “key contacts were with hospital boards, the departments of Health and Education and, increasingly the Native Department” (Tennant, 2007, p.101). The demarcation between the New Zealand Crippled Children Society and the State was clearly defined with the “function of the State to care for the crippled child; it was the special privilege of the Society to look after the interests of the crippled child” (Annual report, 1941/1942).

Such an organisation as ours, keeping as it were, a little ahead of the State and taking advantage of its independence, can investigate and

try out new methods alike in the sphere of clinical work and of the training and employment of the disabled. (Annual Report 1938/1939)

In the early years of the New Zealand Crippled Children Society the relationship between the Society and the State “was shaped not by legislation but by less formal processes of interaction - conversations between influential men, and politicians’ awareness of public sympathies” (Tennant, 2007, p. 102). “The Crippled Children Society (CCS) ... provides another perspective on arrangements between government and the voluntary sector-one where the charitable organisation retained greater distance while still receiving government legitimisation” (Tennant, 2007, p. 100).

This relationship changed over the following decades and the arrival of the contract culture altered the balance of power. When in the early years the New Zealand Crippled Children Society covered half of its costs through philanthropists’ gifts and donations, CCSDA today is overwhelmingly dependent on government funding. Audits, regulations and directives by government dominate the relationship between CCSDA and the State now.

Voluntary organisations have always been innovative “testing grounds for state subsequent advance” (Tennant, 2007, p.120) and if there was not enough finance, government help was required and expected (Tennant, 2007). The three elements of the relationship between non profit organisations and the State manifest in CCSDA’s case as: service delivery and development as complementary, the move to independent income with social entrepreneurship as supplementary and social change and alternative ideas for social policy as adversarial.

Summary

The analysis has shown that CCSDA has moved from a philanthropic model to an activist model, influenced by and influencing societal changes in

Aotearoa New Zealand throughout its history. The three core documents - the Treaty of Waitangi, the New Zealand Disability Strategy and the UN Convention on the Rights of Persons with Disabilities - determine the parameters of future developments of CCSDA, signalling a bicultural and multicultural organisation under the strategic leadership of disabled people and their allies. Actions include quality service provision, advocacy based on issues identified through direct connection with disabled people and an up-to-date social change agenda, which incorporates policy advice to government and political parties, research and the introduction of innovative solutions for an inclusive society in Aotearoa New Zealand.

The last chapter will present concluding thoughts and recommendations. The three published histories, their authors and contributors, and the motivation behind the histories are presented. The thesis will close with recommendations, acknowledging achievements of the historical New Zealand Crippled Children Society, NZCCS and CCS Disability Action.

Chapter Eight: Concluding thoughts and recommendations

This research posed the question about the extent of influence by the popular understanding of impairment and disability, the bicultural composition of society in Aotearoa New Zealand, the disability rights movement and government policy from 1935 to 1945 and from 1997 to 2008 on CCSDA. The analysis of the data confirmed that CCSDA has progressed on the path from charity to social action and that it had a positive influence on the inclusion of disabled people in Aotearoa New Zealand.

Human interaction has to be judged in the historical context of a society and move away from mostly negative judgements to positive acknowledgment of people's goodwill and good intentions. This does not exclude critical analysis, but both viewpoints have to be acknowledged.

Past historical writing on the voluntary sector often reflected notions of 'social control', grounded in Marxist theory. These saw voluntary work as class-ridden, largely to be interpreted in terms of authoritarian interventions, insensitive pieties and do-gooding ladies. A more complex view has now emerged which acknowledges altruism and reciprocity as well as social control. (Tennant, 2007, pp. 14-15)

The various histories of CCSDA show all of these elements and previous histories of the Society have to be viewed in their historical context. The authors of these histories in their various historical periods and their motivation for the interpretations they present have to be acknowledged.

Histories of CCSDA

The three published histories of the New Zealand Crippled Children Society and NZCCS are considered next. Carey's book (1960), the typed manuscript

(1984) and the pictorial booklet (1995) and their authors, other contributors and their motivation in their respective historical context offer interesting conclusions. The analysis of the previous histories of CCSDA led to the following concluding thoughts:

- Carey's history of the New Zealand Crippled Children Society of 1960 was written to glorify the charitable work of doctors, rich philanthropists and other benefactors, mostly from New Zealand's and other Commonwealth countries' upper classes. Welfare Officers, later called Field Officers are praised for their supporting roles and rewarded with funded overseas trips to further their education. 'Crippled children' and their families are confirmed in their roles of passive recipients and are expected to be grateful and to surrender to total control of professionals and well-meaning volunteers over medical treatment, education and vocational training.
- The typed manuscript from 1984, which does not acknowledge an author, was compiled by National office bureaucrats justifying their existence. The tension between the branches doing the 'real work' and the National Office in Wellington trying to assert power over service delivery led to this history. The work of the National Office such as lobbying for improved access to communities nationwide, disability awareness in society and inclusion of disabled people's needs in government policy was highlighted in this history. The 1984 history mentioned the foundation of the DPA briefly at the end but did not acknowledge the conflict between the NZCCS and disabled people doing their own advocacy. Disabled people are portrayed as people to be pitied and supported and even professional disabled people in the management of the organisation at the time felt patronised.
- The pictorial history of 1995 celebrated 60 years of New Zealand CCS formerly New Zealand Crippled Children Society and its production was financed by rich benefactors such as Lady Gillies. The National Office

information service compiled the historical photos and documents and Board members such as Maurice Priestley represented the disabled voice. There was emphasis on the Treaty of Waitangi as a guiding document for NZCCS and kowhaiwhai designs for each region were displayed. Although NZCCS depicted itself as a consumer driven organisation and the influence of disabled individuals was evident, there was no disability rights voice prominent and no linkage to theories or models of disability as the underlying philosophy of NZCCS.

Looking at the three histories of CCSDA led to the conclusion, that a new history from the perspective of the social model of disability with major involvement of disabled people and their allies is overdue. Other recommendations such as the continuation of both service provision and social change agenda, the emphasis on disabled children's rights at the forefront of CCSDA's thinking in close cooperation with disabled adults and the acknowledgement of disabled people's contribution to CCSDA and society as a whole conclude this thesis.

Observations and recommendations:

75 years of history, from charity to social action

CCS Disability Action has a proud tradition as an innovative disability organisation. A high standard of service provision was traditionally a marker for CCSDA and Lady Gillies referred to personal sacrifices by her husband and other philanthropists in order to ensure quality. Tom and Marie Johnson confirmed that a lack of money did not stop the creation of services identified as crucial for disabled children and young adults.

Maurice Priestley's lifelong connection with CCSDA led to a critical analysis of historical developments in the service provision and to active participation in national and local governance to ensure positive changes. Viv Maidaborn as CEO guided CCSDA's first steps as a social entrepreneur

seeking opportunities for independent funding. Ruth Jones and Paul Gibson commented on the fruitful cooperation between CCSDA and disabled people's organisations and the successful influence on government policy and on major contributions to the wording and content of the UN Convention on the Rights of Persons with Disabilities (2006).

What started as the New Zealand Crippled Children Society in 1935 with a philanthropic approach has blossomed into CCS Disability Action with a social change agenda and CCSDA can be proud of its history.

Recommendation: It is time to document CCSDA's journey in a comprehensive history which includes the philosophical foundations of the various eras and provides a new perspective with disabled people as witnesses, contributors and authors.

Quality service provision parallel with a social change agenda

Both quality service provision and the social change agenda's political lobbying and advocacy work are acknowledged as essential by all research participants. Day to day experience of difficulties living with impairment, frustrations with equipment, modifications and service providers combined with discriminatory practices in society, provide the lobbying and advocacy work with real stories. Both parts of CCSDA's operation are regarded as crucial.

Recommendation: Create a strategic framework which incorporates both quality service provision and social change agenda based on the UN Convention on the Right of Persons with Disabilities (2006).

Disabled leaders in CCSDA as champion for the rights of disabled children

Historically the New Zealand Crippled Children Society advocated for 'crippled children' and CCSDA is going "back to the roots with a

twist” (Paul Gibson), reviving the strength of the CCSDA model which is seen by Paul Gibson as defending the rights of disabled children. In the early history of the New Zealand Crippled Children Society philanthropists and doctors looked after disabled children; now disabled adults are standing up for disabled children’s rights. Viv Maidaborn as the CEO in conjunction with the policy team including Ruth Jones and Paul Gibson lobbied for policies protecting vulnerable disabled children. Reaching disabled children and families whanau as early as possible can make the biggest difference (Paul Gibson) and set the right course for a happy and successful life as adults.

Recommendation: CCSDA has to go “back to the roots with a twist” (Paul Gibson) as a recognised champion for the rights of disabled children whilst working with disabled people across all ages. Both elements combined signify the strength of the CCSDA model.

Acknowledgment of disabled people’s contribution to society and to CCSDA

The example of disabled people excelling in many sectors of society is crucial. Celebrating successes of disabled people - not only when the Paralympics are on and in a way that conveys ‘aren’t they brave’ - in the genuine spirit that all people have mauri or life force, as expressed in the CCSDA Maori Mission statement. CCSDA has three core documents - the Treaty of Waitangi, the New Zealand Disability Strategy and the UN Convention on the Right of Persons with Disabilities. According to these, CCSDA has to advocate for human rights for disabled people and acceptance as valued and contributing citizens in a truly bicultural Aotearoa New Zealand.

Recommendation: Highlight achievements of disabled people and help build a society where all people’s mauri is valued and all people are able to contribute.

Endings

The contribution disabled people make to society as a whole, to their community and to CCSDA can be seen everywhere and has to be publicly acknowledged and celebrated. The realisation of the value of disabled people's contribution to CCSDA is obvious now, but it was a slow evolution of thinking:

- From the first involvement of disabled people in the New Zealand Crippled Children Society from the late 1960s as middle managers, feeling the patronising air of the organisation
- To early pockets of acceptance from the late 1980s in New Zealand CCS, with disabled people on advisory panels but still dominated by able bodied professionals
- To acceptance of excellence with highly skilled disabled people in the policy team of CCS Disability Action, leading strategic innovation in the mid and late 2000s.

Leaving the world better than before because of our contribution is an important goal for most people. Most people interpret making a contribution as taking action; it is crucial to acknowledge another form of making a contribution to society, community and family whanau. Disabled people with high and complex needs and their contribution by being present, teaching patience and showing true human spirit, should be accepted as a valuable contribution to society, adding to the human diversity of Aotearoa New Zealand. CCS Disability Action has to continue advocating for the rights of disabled children and strengthening the cooperation and partnership with all disabled people, to achieve true social change and a truly inclusive, diverse society in Aotearoa New Zealand.

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Appendixes

Appendix 1

Consent Form

Name: _____

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 can ask further questions at any time.

I agree to provide information to the researcher on the understanding that I will be identified in the thesis and any published material from it.

I agree to the recording of my interview and I understand that I can request that the recording be stopped during the interview.

I agree to participate in this project under the conditions outlined in the information sheet.

Signed: _____ Date: _____

Full Name - printed _____

Appendix 2

Information Sheet (Participant)

Researcher Introduction

My name is Mathilda Schorer and I am currently working on a thesis for a Master of Philosophy in Social Policy. My supervisors for the project are Dr. Martin Sullivan and Dr. Mary Nash from the School of Health and Social Services.

The contact details are

Researcher: Mathilda Schorer

768 Te Onepu Road
RD 4 Hastings 4174
tirohia@paradise.net.nz
phone 06 8749756
text 027 2185661

Supervisors: Dr. Martin Sullivan and Dr. Mary Nash

School of Health and Social Services
Massey University
Private Bag 11 222, Palmerston North
Phone 06 350 5799

My interest in social policy relating to disability issues was instigated by a lived experience of disability of a close family member and led to a Postgraduate Diploma of Arts majoring in Disability Studies at Massey University. Involvement in the governance of CCS Disability Action, interest in the disability rights movements in Aotearoa New Zealand and Germany and social policy development regarding the rights of disabled people nationally and internationally led to the proposed research project.

Project description and Invitation

The aim of the research is to trace the social history of CCS Disability Action, a disability organisation in Aotearoa New Zealand. The preservation of historic voices and the recording of contemporary leaders of the organisation will be used to examine the societal context in the early years of the New Zealand Crippled Children Society and in the last decade of CCS Disability Action (CCSDA).

The social history of CCSDA - spanning two thirds of the previous century and the first decade of this century - provides an ideal platform for the exploration of social policy in Aotearoa New Zealand. One of the major questions is the extent to which the treatment of disabled people in society and the disability rights movement (DRM) influences the development of strategic priorities in this non profit organisation over time. The project's importance also lies in the documentation of disability history in Aotearoa New Zealand.

This is an invitation to you to participate in this research project as one of six interviewees who have been selected on the basis of having historical knowledge, cultural knowledge, lived experience of disability and/or working within the organisation.

Project procedures and Data Management

Individual face to face interviews with six participants are planned. This is a social history and participants will be named in it.

Interviews will be held at a location mutually agreed upon by you and the researcher. This might be in your home, office or boardroom of the researched organisation. The interview will be audio recorded with your permission. The interviews will be transcribed by the researcher. A copy

will be sent to you for your comments, additions or alterations before I begin analysis.

Data will be stored at the home of the researcher in a secure office space and disposed of after 5 years. Participants will be kept informed by the researcher and the completed thesis will be available to them.

Participants' Rights

If you agree to participate in this research project, you will be asked to sign a consent form. As a participant you have the following rights:

You can refuse to answer questions and request termination of recording at any stage

You can withdraw from the project at any time

You can ask additional questions at any time

You can access the completed thesis through CCSDA's library or through the Massey University library.

Project's contacts

Please do not hesitate to contact the researcher and/or supervisors with questions about the project. See contact details on page 1.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/31. If you have any concerns about the conduct of this research, please contact Dr Karl Pajo, Chair, Massey University Human Ethics Committee: Southern B, telephone 04 801 5799 x 6929, email humanethicsouthb@massey.ac.nz.

Appendix 3

Interview schedule

Interview questions

Personal

When was your first involvement in CCS Disability Action, what kind of connection and why?

When was your involvement?

Why did you get involved?

Which services were available when you were involved?

What principles do you think CCS Disability Action had in the days when you first got involved?

Do you think the vision has changed and how?

Do you agree with the direction the organisation has chosen?

Societal treatment of disabled people

How do you envisage inclusion of disabled people? What are the main features of inclusion into society?

Has inclusion of this minority group been achieved and aided by the researched disability organisation?

Are you aware of major achievements by this organisation regarding government policy development in Aotearoa New Zealand?

Has the broadening of the client base been able to avoid discrimination on the lines of gender, race, age, sexuality, severity and kind of impairment and social standing?

Has the ownership of the organisation changed? What powers do the owners of the organisation have over philosophy and policy development?

Do you think that the Disability Rights Movement had a significant influence on the organisation?

Bicultural perspective

Are you aware of a specifically Maori influence on the organisation?

What do you know about bicultural strategies in the organisation?

Are you aware of the discussion regarding biculturalism versus multiculturalism?

General questions

Where do you think the organisation is heading over the next five years?

Do you think it is appropriate that a service provider practises advocacy and promotes social change?

Do you think it is desirable that this organisation extends its activities into social entrepreneurship?

Are there any other comments regarding the research topic you want to make?