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‘Towards Self-Sufficiency’: Public Health Responses to Diabetes in New Zealand c.1920–2000

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ABSTRACT

This thesis examines public health concerns and responses to diabetes in New Zealand, from the first statistical studies in the 1920s to the release of a national strategy in 2000. The focus is on the post-Second World War period when developments in epidemiology, technology, professional interests, consumer advocacy and the changing position of Maori and Pacific people in New Zealand society, indicated that diabetes was a significant public health problem and pointed to potential strategies for intervention. From the 1960s, these strategies involved early detection, lifestyle modification and health service reorganisation. This study explores how these approaches to diabetes reflected contemporary public health techniques, and how they intersected with New Zealand's broader social policy objectives. It illuminates much about the role of the welfare state and individual citizens in maintaining population health, as well as the role of scientific knowledge in policy-making.

Examining responses to diabetes underscores the social and political value of the ideology of 'self-sufficiency' in mid to late twentieth-century New Zealand, and its limitations. Modern patient education, which emerged in the 1970s, aimed to move people with diabetes 'towards self-sufficiency' in their treatment, and to empower them to take responsibility for their health and well-being more generally. A similar philosophy underpinned 'diabetic' consumer societies which were first established in New Zealand during the Second World War, that self-help was a civic duty. By the closing decades of the twentieth century, several other forms of 'self-sufficiency' influenced responses to diabetes: an epidemiologically informed focus on lifestyle behaviours of the 'at risk', neoliberal ideas of individual responsibility and state service failure, Maori self-determination and community development.

New Zealand's responses to diabetes reflected its particular history of the welfare state and Maori and Pacific communities, but they also existed within broad international trends. Much of the historiography on diabetes has focused on the expansion of medical surveillance; through focusing on consumer groups and including the voices of other under-studied actors – nurses, dietitians and community health workers – this thesis contributes fresh perspectives on diabetes and public health in twentieth-century New Zealand and internationally.

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LIST OF ABBREVIATIONS

ACAS	Auckland Council Archives South
ADA	American Diabetes Association
AJHR	<i>Appendices to the Journal of the House of Representatives</i>
AHB	Auckland Hospital Board
AHBs	Area Health Boards
ANA	Agencies for Nutrition Action
ANZA	Archives New Zealand Auckland
ANZC	Archives New Zealand Christchurch
ANZW	Archives New Zealand Wellington
ATL	Alexander Turnbull Library
BDA	British Diabetic Association
DANZ	Diabetic Association of New Zealand
DNZ	Diabetes New Zealand
HFA	Health Funding Authority
IDDM	Insulin-Dependent Diabetes Mellitus
IDF	International Diabetes Federation
IGT	Impaired Glucose Tolerance
MBL	Macmillan Brown Library
MCC	Manukau City Council
MP	Member of Parliament
MRC	Medical Research Council
NCHB	North Canterbury Hospital Board
NHF	National Heart Foundation
NIDDM	Non-Insulin-Dependent Diabetes Mellitus
NPAD	National Plan of Action on Diabetes
NZBMA	New Zealand Branch of the British Medical Association
NZDA	New Zealand Diabetes Association
NZDF	New Zealand Diabetes Foundation
NZDWA	New Zealand Diabetic Welfare Association
NZMJ	<i>New Zealand Medical Journal</i>
NZNA	New Zealand Nurses Association
NZNO	New Zealand Nurses Organisation
NZPD	<i>New Zealand Parliamentary Debates</i>
NZSSD	New Zealand Society for the Study of Diabetes
PHC	Public Health Commission
RHAs	Regional Health Authorities
SADC	South Auckland Diabetes and Asthma Centre
SADP	South Auckland Diabetes Project
TIMS	Tokelau Island Migrant Study
UKDPS	United Kingdom Prospective Diabetes Study
WHO	World Health Organization

INTRODUCTION

*Diabetes is of growing importance in this country, and, as it strikes one as an essentially preventable disease, it is time something was done to prevent it.*¹

In 1925, the first published statistical analysis of diabetes in New Zealand documented a thirteen-fold rise in the number of deaths from the disorder between 1872 and 1922. Diabetes was the twelfth leading cause of death. The study's author, Dr L.C. McNickle, suggested that there was further cause for alarm, however, because 'a great many more' people with diabetes died from conditions they were susceptible to developing: 'arteriosclerosis, nephritis, boils and abscesses, and, above all, tuberculosis'.² Moreover, as McNickle – who had diabetes himself – noted, 'diabetes is responsible for a great deal of invalidism, unhappiness, and expense, apart from the deaths it causes'. He argued that even though little was known about the aetiology of diabetes, his clinical experience provided enough evidence to show that it was 'time something was done to prevent it', namely, '(1) early diagnosis, and (2) prevention of obesity'.³

Concerns like McNickle's, about an increase in 'an essentially preventable disease' responsible for significant, though often hidden, human, social and economic costs, came to characterise public discourse about diabetes by the end of the twentieth century. This thesis investigates the development of these public health concerns about diabetes in New Zealand, and responses to them. Although beginning with early statistical studies like McNickle's in the 1920s, the focus is on the post-World War Two period up to the release of a major national management strategy in the year 2000. Indeed, that McNickle had such concerns about prevention in 1925 is remarkable for the fact he did so at a time flush with excitement

¹ L.C. McNickle, 'Diabetes in New Zealand – discussed etiologically', *New Zealand Medical Journal* (NZMJ), 24, 1925, p.245.

² *Ibid.*, p.243.

³ *Ibid.*, p.252.

about what, as one New Zealand doctor put it, was ‘the most valuable therapeutic discovery of modern times’: insulin.⁴

Insulin revolutionised the treatment of diabetes in the Western world in the 1920s. Prior to this, in the early twentieth century, treatment for the metabolic condition was primarily dietetic. Most commonly, physicians prescribed a diet high in fat and low in carbohydrate as this appeared to have some effect in reducing diabetes physical symptoms of excessive urination, hunger, thirst and wasting, and their associated bio-markers of urine sugar (glycosuria) and elevated blood sugar levels (hyperglycaemia). Diets were more effective for older, overweight, symptomatically ‘mild’ patients than the young ‘severe’ patients whose symptoms emerged rapidly and rarely survived more than a year or two even on the bleakest ‘starvation’ diet. Most severe patients succumbed to ketoacidosis where the body, unable to process glucose for energy, turned to burning fat, which left poisonous waste products (ketones) to build up in the body.

Scientific understanding of diabetes had advanced significantly over the previous decades. Since the eighteenth century, various authorities had proposed the kidneys, stomach and liver as the disordered organ responsible for diabetes but, in the 1890s, animal experiments proved that diabetes stemmed from the pancreas. These experiments demonstrated that removing a dog’s pancreas caused the dog to develop diabetic symptoms. They also established that immediately implanting part of the pancreas back under the skin of the dog would stop it developing hyperglycaemia; once the implanted tissue degenerated or was removed, hyperglycaemia appeared. For the next thirty years, researchers’ worked to find an ‘internal secretion’ from clusters of cells within the pancreas, named the islets of Langerhans (beta

⁴ H. Bayldon Ewen, ‘Insulin in the treatment of diabetes’, NZMJ, 25, 128, August 1926, p.202.

cells), which they believed controlled carbohydrate metabolism. In 1921, a Canadian team isolated this ‘antidiabetic substance’, the hormone insulin, and developed a purified extract from cow pancreases to treat humans.⁵

By late 1923 adequate supplies of insulin were available to treat patients in many countries, including New Zealand. Medical literature that depicted emaciated children brought back from death’s door attracted public attention to the apparent cure. The discovery of insulin thus earned a reputation as symbolic of the golden age of scientific medicine.⁶

Insulin was no cure but rather transformed diabetes from an acute to a chronic illness. As young patients lived longer, they developed eye disease (retinopathy), kidney lesions (nephropathy) and nerve damage (neuropathy). Blindness, renal failure, difficulties with wound healing and infection, and death by middle age were common results. These complications also affected older people with diabetes but their major problems were from macrovascular damage (from faulty fat metabolism). Many suffered, and died, from heart attacks or stroke, while gangrene led to lower limb amputations.⁷ Whether it was possible to prevent such long-term complications remained a highly controversial medical and scientific debate for decades but, in general, the aim of treatment was to remove symptoms and reduce hyperglycaemia.⁸ Too much insulin, however, could lead to dangerously low blood sugars (hypoglycaemia) which caused seizures and loss of consciousness. People with diabetes

⁵ These details constitute an abbreviated version of the standard historical narrative of ‘the road to insulin’. For a succinct textbook overview, see Donald M. Barnett and Leo P. Krall, ‘The History of Diabetes’, in C. Ronald Kahn, Gordon C. Weir, George L. King, Alan C. Moses, Robert J. Smith and Alan M. Jacobsen, eds, *Joslin’s Diabetes Mellitus*, 14th edition, Boston, 2005, pp.1–5.

⁶ Allan M. Brandt and Martha Gardner, ‘The Golden Age of Medicine?’, in Roger Cooter and John Pickstone, eds, *Companion to Medicine in the Twentieth Century*, London, 2003, pp.21–37.

⁷ Robert Tattersall, *Diabetes: The Biography*, Oxford, 2009, pp.115–16.

⁸ On the ‘control controversy’, which was particularly acrimonious in the United States, see Aaron Pascal Mauck, ‘Managing Care: The History of Diabetes Management in Twentieth Century America’, PhD dissertation, Harvard University, 2010, pp.245–303; Jeremy A. Greene, *Prescribing by Numbers: Drugs and the Definition of Disease*, Baltimore, 2007, pp.115–48; and Harry Marks, *The Progress of the Experiment: Science and Therapeutic Reform in the United States, 1900–1990*, New York, 1997, pp.197–228.

therefore negotiated a challenging life-long path of lifestyle modification that involved dietary control, self-administration of insulin and regular testing of their urine sugars.⁹

Not all people with diabetes responded to insulin. In the 1930s, British physician Harold Himsworth developed a test that identified the principle of insulin sensitivity in differentiating two major types of diabetes. Himsworth found that young, thin patients' blood sugar dropped with a small dose of insulin and they could easily become hypoglycaemic, while older, fat patients needed significantly larger doses to achieve the same drop in blood sugar and did not get hypoglycaemia.¹⁰ It was not until 1951 that it became possible to measure insulin in the blood and confirm this principle: juvenile-onset patients were insulin deficient, whereas older, overweight patients had something interfering with the action of insulin – they were insulin resistant.¹¹ For the insulin-resistant adult-onset patient the mainstay of treatment was still diet, but the type of diet varied and prescription did not guarantee practice. Meanwhile, decades of research and commercial investment to find a more user-friendly oral form of insulin bore fruit in the mid-1950s, not as the hoped for insulin replacement, but a separate treatment for adult-onset patients: hypoglycaemic tablets (sulphonylureas and biguanides).¹² By the early 1960s these oral medications were in common use as an adjunct therapy to diet for adult-onset patients.

⁹ Some specialists were less demanding of their patients than others; part of the control controversy was the tension between 'tight' advocates who maintained that a strict diet prolonged life, and the 'loose' advocates who believed diet could be liberalised with the advent of insulin and care could be 'purely symptomatic': Barnett and Krall, p.11.

¹⁰ H.P. Himsworth, 'Diabetes mellitus: the differentiation into insulin-sensitive and insulin-insensitive types', *The Lancet*, 227, 5863, 1936, pp.127–30. See also Linda Bryder and Courtney Harper, 'Commentary: More than 'tentative opinions': Harry Himsworth and defining diabetes', *International Journal of Epidemiology*, 42, 6, 2013, pp.1599–1600.

¹¹ J. Borstein and R.D. Lawrence, 'Plasma insulin in human diabetes mellitus', *British Medical Journal*, 2, 4747, 29 December 1951, pp.1541–4; Tattersall, pp.124–5.

¹² Greene, pp.88–98. People with adult-onset diabetes on these medications could now also suffer hypoglycaemia if dosage was incorrect.

While physicians had long made distinctions between different types of patients, there persisted a perception that diabetes was a single disease and universally accepted classification criteria were not in place until the 1980s. The expansion of genetic, epidemiological and immunological research over the 1960s and 1970s suggested the heterogeneity of diabetes and its aetiological differences. Additionally, clinical experience revealed expressions that did not fit typical age or weight-related patterns. In 1974, the discovery of islet cell autoantibodies associated with insulin-dependent diabetes (typically ‘juvenile onset’) led to an understanding that this was an autoimmune condition.¹³ Following the United States National Diabetes Data Group’s 1979 classification scheme, a World Health Organization (WHO) expert committee established the first widely used international nomenclature: Type I insulin-dependent diabetes mellitus (IDDM) and Type II non-insulin-dependent diabetes mellitus (NIDDM).¹⁴ A third category of gestational diabetes described a transitory condition of hyperglycaemia in pregnancy that could lead to birth complications and the later development of NIDDM in the mother. Although acknowledged at the time for over-simplifying a complex metabolic syndrome, the labels Type 1 and Type 2 (the reference to insulin dropped in revised criteria in the late 1990s as many Type 2 do end up needing insulin treatment) are still in use today to describe the most common forms.¹⁵ In New Zealand, and similar Western countries, Type 1 constitutes around 10 per cent of cases and Type 2 the other 90 per cent.

¹³ Gian Franco Botazzo, Alejo Florin-Christensen and Deborah Doniach, ‘Islet-cell antibodies in diabetes mellitus with autoimmune polyendocrine deficiencies’, *The Lancet*, 304, 7892, 30 November 1974, pp.1279–83.

¹⁴ WHO, *WHO Expert Committee on Diabetes Mellitus: Second Report*, Technical Report Series No.646, Geneva, 1980, pp.12–13. For New Zealand’s official statement of interpretation, see D.W. Beaven, P.J. Dunn, R.B. Elliott, P. Fleischl, D.M. Hanna, J.A. Kilpatrick, R.B.W. Smith and M.H. Watson, ‘A new international classification of diabetes mellitus’, *NZMJ*, 13 May 1981, pp.304–6. Gestational diabetes was firmly identified as a separate condition in 1964: J.B. O’Sullivan and C.M. Mahan, ‘Criteria for the oral glucose tolerance test in pregnancy’, *Diabetes*, 13, May/June 1964, pp.278–85.

¹⁵ P.G. Colman, D.W. Thomas, P.Z. Zimmet, T.A. Welborn, P. Garcia-Webb and M.P. Moore, ‘New classification and criteria for diagnosis of diabetes mellitus: position statement from the Australian Diabetes Society, New Zealand Society for the Study of Diabetes, Royal College of Pathologists of Australasia and Australasian Association of Clinical Biochemists’, *Medical Journal of Australia*, 170, 8, 1999, pp.375–8. After this introductory chapter I will use the terminology appropriate to the period discussed and/or as indicated in the primary sources.

From the late 1970s, the therapeutic advances for diabetes were exponential. New dietary recommendations prescribed lower fat and higher carbohydrate levels in line with those for the general population. New technology enabled people with diabetes to monitor their condition through instant, more accurate blood glucose testing instead of the messy, rough approximation of urine testing. The HbA1C test also gave health care providers a better picture of their patients' blood glucose control as it measured an average level across a two-month period. For people with Type 1 diabetes, new insulin analogues and long-lasting insulin, more user-friendly insulin delivery systems such as 'pens' and continuous subcutaneous infusions through pumps became available in the 1980s and 1990s. For people with Type 2, several additional oral medications came on the market. Meanwhile, diabetes' most feared consequences had become more treatable. Surgical advances reduced amputations for gangrenous limbs, laser therapy for diabetic retinopathy, renal dialysis and transplantation for kidney failure, coronary bypass procedures, and pharmaceutical interventions for hypertension and even Viagra for impotence.¹⁶

Yet, at the end of the twentieth century, many considered that New Zealand, like much of the world, faced an accelerating epidemic of diabetes that would expand the social, human and financial costs of the disorder, costs similar to those which McNickle had highlighted several decades earlier. In those intervening decades, epidemiological research had determined 'at-risk' groups, as well as asymptomatic and 'prediabetic' states of abnormally high blood glucose levels. Those with the disorder faced not only the financial expense of life-long care, but social challenges and stigma, although the nature of these changed over time. Perennially difficult to quantify, diabetes and its complications were a major burden on national health care resources and the human toll in death and morbidity had continued to increase,

¹⁶ For a good overview of these therapeutic developments, see Tattersall, pp.159–73.

particularly for New Zealand's indigenous Maori and newer Pacific populations. While McNickle's calls for early diagnosis and prevention of obesity had resonances throughout the decades, the means to achieve these changed. By the 1990s, environmental and socio-economic arguments began to challenge a long-established focus on lifestyle. The premise of moving people with, or at risk of diabetes 'towards self-sufficiency' – empowering them to take responsibility for their health and welfare, however, was an enduring theme.¹⁷

Central to this thesis is an exploration of how such responses to diabetes reflected wider shifts in public health ideology, and how they intersected with New Zealand's broader health and social policy objectives. These issues are connected to questions about the roles of the welfare state and individual citizens in maintaining population health, as well as questions about the influence of scientific knowledge, or otherwise, in policy-making. Diabetes is a useful prism through which to examine these issues as it had a multifaceted and ongoing impact in the areas of public health and welfare provision over the twentieth century: from Social Security benefits for needles and syringes, to early detection campaigns, to patient education to community development. Moreover, growing distinctions between different types of diabetes and at-risk groups presented additional complexities to public health responses, notions of health citizenship and public perceptions. As New Zealand's responses to diabetes drew on, and contributed to, international trends this study has wider relevance to a growing historical literature on diabetes and late twentieth century public health.

Diabetes historiography

Until the 1990s, the major focus of historical studies of diabetes was the paradigmatic discovery of insulin. Since then, histories have looked, often critically, at therapeutic

¹⁷ Alison Helm, 'The Christchurch Hospital diabetes educational programme', *New Zealand Nursing Journal*, 70, 7, July 1977, p.31.

developments and scientific understandings about diabetes and their impact on patients and society. The current diabetes ‘epidemic’ has inspired popular literature attempting to explain its historical origins and find solutions, while recent doctoral theses have explored the historical evolution of contemporary diabetes management practices over the twentieth century.

The history of diabetes was traditionally a story of progress towards what many consider one of the most significant turning points in modern scientific medicine – the discovery of insulin at the University of Toronto in 1921. Canadian medical historian Michael Bliss noted in his 1982 book on the discovery that to physicians at the time, the effect of insulin on patients with severe diabetes was ‘one of the genuine miracles of modern medicine’.¹⁸ The discovery, quick standardisation and manufacture, and controversial awarding of the Nobel Prize to only two of its discoverers, were subject to historical scrutiny for the next fifty years. Medical researchers, and the men involved, recorded the early historical accounts of the discovery.¹⁹ Thus, they fitted nicely into the traditional medical history positivist grand narrative of scientific progress told from within the profession.²⁰ As did the first ‘general’ history of diabetes in 1952 in which N.S. Papaspyros, a Greek diabetes specialist, charted the sweeping progress of scientific knowledge from descriptions of the disorder in antiquity to the isolation of insulin.²¹

When Bliss gained access to new primary sources in the late 1970s he adjusted the progressive narrative to one of intense competition, confrontation, political and institutional

¹⁸ Michael Bliss, *The Discovery of Insulin*, 25th anniversary edition, Chicago, 2007, p.11.

¹⁹ *ibid.*, pp.13–17.

²⁰ Gert Brieger, ‘The Historiography of Medicine’, in W.F. Bynum and Roy Porter, eds, *Companion Encyclopedia of the History of Medicine*, Vol. 1, London, 1997, p.24. The history of the introduction of insulin treatment in New Zealand also fitted into this approach: see M.H. Watson, ‘The early days of insulin in New Zealand’, *NZMJ*, 93, 684, 27 May 1981, pp.347–50.

²¹ N.S. Papaspyros, *The History of Diabetes Mellitus*, London, 1952.

machinations. His resultant book thus challenged the heroic (partly self-propagated) mythology of the scientific genius of a little-known young orthopaedic surgeon, Frederick Banting, and medical student, Charles Best; Bliss emphasised the important parts physiologist Professor J.J.R. Macleod, biochemist Bert Collip, and the University of Toronto itself played in the discovery. Following Bliss's lead a number of scholarly articles on the subject and biographies on the researchers explored these and related issues.²²

In 1991, James Wright Presley provided the first large-scale history of clinical ideas and approaches to diabetes in the United States for the period 1880–1990. Presley's doctoral dissertation questioned why, despite rapid advances in treatment, death rates for diabetes remained consistently high throughout the twentieth century. He argued that the predominant drive towards therapeutic rather than preventative medicine held back a reduction in deaths.²³ American medicine continued to manage chronic diseases like diabetes according to an infectious disease model that treated symptoms as they appeared with 'the standard armamentarium of drugs'.²⁴ Presley did not consider the early diagnosis and prevention of diabetes complications as part of preventive medicine yet, as David Cantor has illustrated in relation to twentieth century cancer control, the boundaries between treatment and prevention often blurred, particularly with early detection campaigns.²⁵ Such findings could equally apply to diabetes control.

²² Alison Li, *J.B. Collip and the Development of Medical Research in Canada*, Montreal, 2003; Michael J. Williams, 'J.J.R. Macleod: the co-discoverer of insulin', *Proceedings of the Royal College of Physicians of Edinburgh*, 23, 3, Supplement No.1, July 1993; Henry Best, *Margaret and Charley: The Personal Story of Dr Charles Best*, Canada, 2003; M. Jurdjevic and C. Tillman, 'E.C. Noble in June 1921 and his account of the discovery of insulin', *Bulletin of the History of Medicine*, 78, 4, 2004, pp.864–75; Christiane Sinding, 'Making the unit of insulin: standards, clinical work and industry, 1920–25', *Bulletin of the History of Medicine*, 76, 2, Summer 2002, pp.231–70.

²³ James Wright Presley, 'A History of Diabetes Mellitus in the United States, 1880-1990', PhD dissertation, University of Texas, 1991.

²⁴ *Ibid.*, pp.669–77.

²⁵ *Ibid.*, pp.567–8. David Cantor, 'Introduction' in David Cantor, ed., *Cancer in the Twentieth Century*, Baltimore, 2008, pp.1–35.

Further challenges to the heroic nature of therapeutic advances in diabetes came with Chris Feudtner's research on juvenile-onset diabetes. In a 1995 article, Feudtner considered how physicians grappled with enrolling patients in self-care and surveillance by imbuing the metabolic control of diabetes management with moral values that patients internalised.²⁶ He expanded on this argument in a 2003 book based on his doctoral research into the patient records and correspondence of premier American diabetes specialist – and leading advocate of tight blood sugar and dietary control – Dr E.P Joslin.²⁷ Feudtner, who trained concurrently as an historian and paediatrician, focused on the perspectives of Joslin's patients and how diabetes and its management affected their lives; his account was the first real social history of diabetes, nearly two decades after this had become a standard approach in the history of medicine.²⁸ Feudtner highlighted the 'bittersweet' nature of insulin as it altered both the biological course and social effects of diabetes. Yet, he also made clear that insulin should 'be seen in proper perspective' as 'the core issues of management, control and responsibility' predated insulin in ordering the lives of people with diabetes (Joslin treated his first juvenile-onset patient in 1898).²⁹

Other historians have emphasised how insulin was only one aspect of innovation in the 'supported lives' of people with diabetes, and that the configurations of care in the twentieth century were just as important. British historian Jennifer Stanton has argued that life supported by insulin should not be seen as 'technological high drama, but as a conglomeration of routine tasks involving relationships with family, employer and health workers'.³⁰ In a

²⁶ Chris Feudtner, 'The want of control: ideas, innovations and ideals in the modern management of diabetes mellitus', *Bulletin of the History of Medicine*, 69, 1, Spring 1995, pp.66–90.

²⁷ Chris Feudtner, *Bittersweet: Insulin and the Transformation of Illness*, Chapel Hill, 2003, preface.

²⁸ In 1997 Brieger wrote that the history of medicine's need to consider 'the experiences of patients has by now assumed the status of a cliché': Brieger, p.25.

²⁹ Feudtner, *Bittersweet*, pp.28–29.

³⁰ Jennifer Stanton, 'Supported Lives', in Roger Cooter and John Pickstone, eds, *Companion to Medicine in the Twentieth Century*, London, 2003, p.604.

2002 chapter on organisational innovation in the British National Health Service, Helen Valier and Roberta Bivins have similarly argued that changes to the organisation of care since the 1970s had more of an impact on patient experience than medical advances in treatment. Their discussion of new community-based services for diabetes in the city of Manchester in the 1980s and 1990s demonstrated how different professional groups promoted, and responded to service developments. In particular, Valier and Bivins suggested that the historical recognition of patient compliance, and patient culture, to therapeutic success was an important factor in health professionals' responsiveness to changing patient needs in the community.³¹

Two 'biographies' of diabetes published in 2009 attempted a longer view on therapeutic developments, shifting perceptions of the disorder, and their impact on patient's lives. Early modern medical historian Elizabeth Lane Furdell's *Fatal Thirst* examined diabetes in Britain before the discovery of insulin, while retired British diabetes physician Robert Tattersall's *Diabetes: The Biography* took an overview from antiquity to the present day. Although mostly about the multiple theories and treatments that circulated in the sixteenth to nineteenth-century medical marketplace, Furdell framed her work in relation to contemporary public health concerns; her final chapter examined the 'lingering' effects of insulin and an 'epilogue' considered continuing themes. In the latter she argued that medical attitudes about patients as lazy or unintelligent and lacking in self-control was 'an anti-diabetic theme that continues to this day'.³² Furdell's main conclusion was that, 'There is no progressive arc to follow in the history of diabetes'.³³ Taking a more progressivist stance and aimed at a popular

³¹ Helen Valier and Roberta Bivins, 'Organization, Ethnicity and the British National Health Service', in Jennifer Stanton, ed., *Innovations in Health and Medicine: Diffusion and Resistance in the Twentieth Century*, London, 2002, pp.37–63.

³² Elizabeth Lane Furdell, *Fatal Thirst: Diabetes in Britain until Insulin*, Leiden, 2009, p.167. Furdell has diabetes herself.

³³ *Ibid.*, p.165.

audience, Tattersall's 200-page biography lucidly connected developments in scientific understanding, treatment and clinical care, with their impact on patients, education and epidemiology. Tattersall acknowledged he had 'excessively' concentrated on 'progress' such as 'new drugs, new insulins, and other technological developments', despite his contention that the arrival of diabetes nurse specialists in the 1980s was of greater importance in improving care 'than any other innovation or drug'.³⁴ These nurses received two paragraphs, while a 'Postscript' acknowledged the contributions of 'extraordinarily resourceful patients', many examples of which Tattersall had personally encountered as a clinician.³⁵ This latter point is interesting in light of his assertion that until the 1970s, 'Patients' views were not solicited'.³⁶ These biographical works, along with Feudtner's, Stanton's, and Valier and Bivins', invite questions about the shifting relationships between health professionals and people with diabetes over the twentieth century, and the extent of paternalistic attitudes in diabetes management, which this thesis will address using New Zealand examples.

A major purpose of biographical accounts of diabetes has been to explain how diabetes went from being a relatively obscure disease to what is now considered a global epidemic, and what can be done about it. Tattersall devoted a chapter to this, in which he explained the development of diagnostic techniques, epidemiological methods and the scientific theories about the place of genetics and modern lifestyles that promote sedentary behaviour and excessive food consumption.³⁷ Tattersall implied that the solution lay in 'trying to find drugs to "cure" obesity' because changing an environment that promoted obesity would be too

³⁴ *Ibid.*, p.150. Other historical studies have referred to the significance of diabetes nurses specialists, and the greater professional power of non-medical health professionals in diabetes management in the late twentieth century, but not explored their perspectives in detail: see Mauck, p.310 n.13 and Valier and Bivins, pp.42–43.

³⁵ Tattersall, pp.197–200.

³⁶ *Ibid.*, p.197.

³⁷ *Ibid.*, pp.178–96.

difficult ‘in a free society’.³⁸ In 2010, investigative journalist Dan Hurley’s *Diabetes Rising: How a Rare Disease Became a Modern Pandemic, and What to Do about It*, attempted to find the answers to its title’s questions by highlighting several ‘groundbreaking [sic] discoveries that have rarely been shared with the public’.³⁹ This ‘pandemic’ was not just of Type 2; rates of Type 1 had also been rising since the late twentieth century. After a survey of the rise from antiquity to the present day, Hurley detailed five ‘heretical’ explanations: that an ‘accelerator’ effect of weight gain, or persistent organic pollutants in the environment, were causing both forms to rise, and that cow’s milk baby formulas, low vitamin D, or not enough exposure to germs triggered Type 1.⁴⁰ Having Type 1 himself, Hurley was motivated to find solutions that stopped blaming ‘diabetics’ and imploring them to ‘try harder’.⁴¹ However, in Hurley’s account, vested interests in particular research fields, the conservatism of professional organisations, bothersome regulations and unwilling insurance companies were holding up what he considered the most promising solutions: the artificial pancreas, bariatric surgery for Type 2, a pill for Type 1 and ‘the public health cure’ (taxing the food industry and creating environments that encouraged activity). In keeping with his ‘heroes and villains’ approach, Hurley saw a need for more citizen advocates to join the ‘relatively small number ... struggling against orthodoxy to bring it [diabetes] to its knees’.⁴²

Meanwhile, medical anthropologists in the last decade have challenged biomedical ‘racialized’ explanations of the diabetes epidemic that focused on the ‘faulty genes’ and ‘faulty diets’ of indigenous peoples, who became greatly more affected by diabetes over the twentieth century than

³⁸ *Ibid.*, p.196.

³⁹ Dan Hurley, *Diabetes Rising: How a Rare Disease Became a Modern Pandemic, and What to Do about It*, New York, 2010, quote from dust jacket.

⁴⁰ *Ibid.*, pp.91, 91–180.

⁴¹ Chapter Three is titled, ‘Try Harder: The Rise of Tight Control for Type 1: 1975 to the Present Day’.

⁴² Hurley, pp.xxiii, 265. Hurley ended with a proposal for a new organisation, ‘Citizens United in Resolve to End Diabetes’ (i.e. ‘CURE’). Virginia Berridge has highlighted the ‘heroes and villains’ journalistic model in the history of smoking: Virginia Berridge, *Marketing Health, Smoking and the Discourse of Public Health, 1945–2000*, Oxford, 2007, p.5.

whites. Instead, these accounts focus on the ‘macro-social context in which diabetes originates’, that is, histories of genocide and colonisation were to blame, and indigenous self-determination was the solution.⁴³ Although concerned with the evolution of diabetes into a major public health problem in the twentieth century, apportioning blame and finding solutions are not the intentions of my research; rather, I investigate contemporary understandings and actions to illuminate further how it became such a significant public health issue in New Zealand.

In his 2010 doctoral thesis on diabetes management in twentieth century America, Aaron Mauck suggested that many biographies failed to fully appreciate how medical institutions and approaches ‘have made diabetes what it is today’.⁴⁴ While disease management is a contemporary term for population-based strategies centred on risk assessment, ongoing monitoring and continuous quality improvement, Mauck argued that this approach had historical roots in the efforts to align clinical, epidemiological and policy perspectives into ‘a coherent system of care’ for diabetes over the twentieth century. He found that this alignment often failed as researchers, clinicians, patients, insurers and policy-makers had different understandings of diabetes and perceptions of risk, while the nature of the disorder resisted standardised approaches in the real world. Mauck did not deny real changes in the disease burden, but his focus was on the way that medical and institutional developments shaped not only patient experience (becoming largely invisible as diagnosis and treatment decisions moved from symptoms to blood sugar levels), but the very definition of diabetes (for example, including the asymptomatic) and thus the public health burden.⁴⁵ In this respect, Mauck’s work built on Jeremy Greene’s 2007 examination of the pharmaceutical industry’s

⁴³ Mariana Leal Ferreira and Gretchen Chelsky Lang, eds, *Indigenous Peoples and Diabetes: Community Empowerment and Wellness*, Durham, NC, 2006, pp. xviii, 8. There is a much longer history of racialisation of diabetes: in the nineteenth century diabetes was known as ‘the Jewish disease’. For a cultural history perspective, see Sander L. Gilman, *A Cultural History of Obesity*, Cambridge, 2008, pp.101–22.

⁴⁴ Mauck, p.24.

⁴⁵ *Ibid.*, pp.23–24.

role in expanding the boundaries of chronic disease; Greene made a case study of the marketing of oral hypoglycaemic ‘Orinase’ (Tolbutamide) in fuelling a movement for ‘finding the hidden diabetic’.⁴⁶ Mauck also examined this movement by looking at the roles of the organisation of diabetes physicians, the American Diabetes Association (ADA) and chronic disease epidemiology.⁴⁷ Greene and Mauck focused on the American context, however, and the international dimensions of this pertinent aspect of the public health history of diabetes deserves more attention, which this thesis will investigate through providing another case study of detection surveys conducted in New Zealand.

Epidemiological surveys were critical to shifting understandings of the nature of diabetes and its impact on America’s indigenous and immigrant communities in the second half of the twentieth century, as Stephanie Stegman demonstrated in her 2010 doctoral dissertation on diabetes in the American Southwest.⁴⁸ Stegman proposed to move from the metaphor of control in diabetes management to action, of taking control via research and public policy. In particular, she examined how the ‘fact’ local indigenous and Hispanic populations were ‘at risk’ of diabetes entered community and scientific understandings of the disorder. In her account, community studies not only aided the accumulation of universal knowledge about diabetes, but also, by the 1980s, opened up opportunities for the wider recognition of a public health crisis. State policy and programmes to control diabetes focused on the community – geographically or racially defined – in what Stegman described as an alignment of epidemiological understandings of risk and concerns for cost containment. Building on Stegman’s analysis, this thesis investigates the role of epidemiological studies in the

⁴⁶ Greene, pp. 83–114.

⁴⁷ Mauck, pp.136–244.

⁴⁸ Stephanie Stegman, ‘Taking Control: Fifty Years of Diabetes in the American Southwest 1940-1990’, PhD dissertation, Arizona State University, 2010.

identification of New Zealand's high-prevalence ethnic groups and their impact on public health approaches to diabetes.

Social stigma has been another feature of shifting understandings and approaches to diabetes in the twentieth century. Mauck discussed how misunderstandings about the risk of hypoglycaemic episodes from insulin usage, where the person could seem drunk or lose consciousness, encouraged perceptions that diabetes was inherently risky. This, and statistical risks associated with complications and reduced longevity, contributed to insurance and employment discrimination affecting all people with diabetes whether they took insulin or not. Mauck examined how the ADA embarked on social advocacy campaigns in the 1940s and 1950s that promoted an image of 'good diabetics' that followed medical advice as a means to reduce stigma and discrimination.⁴⁹ In a 2013 article, Arleen Tuchman questioned why eugenic concerns about the spread of the 'defective' genes of people with diabetes from the 1920s to 1950s did not result in eugenic solutions – sterilisations or strong advice not to reproduce – when these were occurring for other conditions in the United States. She argued that just as racial and class stereotypes could create stigma, they could also have a protective effect. As a disease associated with the white middle-class in the early to mid-twentieth century, 'possession of a defective gene mattered less than the perception of one's contribution to society'.⁵⁰ Anthropologists have looked at these issues in relation to the hypothesised genetic susceptibility to diabetes of indigenous populations in various countries in the latter twentieth century. Perceptions that these groups were destined to develop diabetes resulted in a lack of government interest in preventive public health measures.⁵¹ Alternatively, as noted above, Stegman saw a targeted policy response in the American Southwest. Both

⁴⁹ Mauck, pp.192–244.

⁵⁰ Arleen Marcia Tuchman, 'Diabetes and "defective" genes in the twentieth century United States', *Journal of the History of Medicine and Allied Sciences*, 70, 1, January 2015, pp.1–33.

⁵¹ Ferreira and Lang, p.4.

approaches could create stigma.⁵² New Zealand's experience, as explored in this thesis, could add further insight into how, why and to what effect public perceptions of people with diabetes changed over the course of the twentieth century.

The most recent historical study of diabetes, Martin Moore's 2014 doctoral thesis, examined the evolution of diabetes management in Britain c.1910–1994. Moore considered that, despite a patient-centric rhetoric in diabetes management, medical discourse always focused on the role of doctors in achieving their desired patient outcomes, which strengthened with the development of bureaucratic measures for structuring care from the 1970s.⁵³ Moore's work demonstrated how medical professionals, concerned with quality care, developed bureaucratic tools such as registers, guidelines, and audit as more diabetes care shifted from hospital clinics to general practice, and down the hierarchy of medical labour. In his account, a neoliberal government, which viewed constricting doctors' decision-making as a way to improve cost-efficiencies in the 1980s and 1990s, then took up these bureaucratic tools to 'discipline' the profession. In explaining these developments, Moore emphasised the role of elite professional bodies, working across government and international networks through British involvement in the WHO. He thus questioned a common interpretation that the government forcibly restricted doctor's clinical autonomy during a period of acrimonious health reforms. Moore contended the resultant 'target–guideline–audit approach to public health', for which strategies of diabetes management had been a model, further marginalised socio-economic determinants of health in British public health.⁵⁴ Using the New Zealand experience, this thesis builds on Moore's work in relation to new care structures from the

⁵² See the discussion of Maori health citizenship and stigma in the next section of this introduction.

⁵³ Martin Moore, 'A Question of Control? Managing Diabetes and Its Professionals in Britain, c.1910–1994', PhD thesis, University of Warwick, 2014, pp.29, 157–9; 246–7; 257–60.

⁵⁴ *Ibid.*, p.269. Moore develops these arguments fully in chapter five.

1970s and in examining connections between international networks, political ideology and public health.

In New Zealand, the literature on diabetes is limited to self-published histories of local diabetes societies and a book the national association, Diabetes New Zealand (DNZ), commissioned to commemorate its fortieth anniversary in 2002.⁵⁵ Although having nostalgic and progressivist sentiments, these works relayed memories of how organisations of people with diabetes and their families were involved in the social and public health responses to diabetes in New Zealand and, in this way, they are valuable resources. Investigating the records of DNZ, alongside official government archives, brought these roles into even sharper relief and emphasised the importance of the interactions between government and the voluntary sector in responses to diabetes.

Such organisations also existed around the world; the first formed in Belgium in 1926, and were part of an international network (the International Diabetes Federation (IDF) was established in 1952) that promoted the welfare of people with diabetes and the acquisition of scientific knowledge. Despite these functions, and active consumer involvement, the international literature has tended to characterise these organisations as simply forerunners to health professionals' wider adoption of patient education strategies in the late twentieth century, or as dominated by physician control.⁵⁶ In his consideration of the ADA's social advocacy campaigns, Mauck suggested patient involvement and reception of the ADA's

⁵⁵ Gordon Rodger, *Diabetes Northland: A Brief History of the First 25 Years, 1979–2004*, Whangarei 2004; Margaret Jamieson, *History of Diabetes Nelson Incorporated: Formerly, The Diabetic Association of New Zealand (Nelson Division), 1957–2005*, Nelson, 2005; Bee Dawson, *Dedicated to Diabetes: Diabetes New Zealand, 1962–2002*, Wellington, 2002. Diabetes Australia also commissioned a history in 1998, written by a prominent Australian diabetologist, which has been useful for comparisons with New Zealand developments: F.I.R. Martin, *A History of Diabetes in Australia*, Melbourne, 1998.

⁵⁶ Leo P. Krall, 'The history of diabetes lay associations', *Patient Education and Counselling*, 26, 1995, pp.285–91; Valier and Bivins; Moore, pp.66–133; Tattersall, p.85.

messages of personal responsibility were based on a set of ‘shared expectations’ between doctors and people with diabetes: they were not just ‘an expression of professional paternalism’.⁵⁷ My study also queries characterisations of physician control.

The historiography on diabetes has expanded significantly since the 1990s in concert with contemporary public health concerns. Moving beyond the heroic discovery of insulin, a predominant focus has been the struggle for control in twentieth century diabetes management. Much of this history has implied a perceived need for the biological control of diabetes was a proxy for social control; paternalistic doctors and the expansion of medical surveillance are recurrent themes. By foregrounding consumer groups, and considering the views of nurses, dietitians, and community health workers, my study offers fresh perspectives on relationships between health professionals, people with diabetes and their families. Investigating diabetes epidemiology, detection drives, policy-making and social attitudes, this thesis also builds on recent scholarship on these subjects in the United States and Britain.

Public Health and Social Policy

This study seeks to contribute to the historiography relating specifically to diabetes, but also to broader changes relating to understandings of public health and social policy in the mid to late twentieth century. As such, it draws on literature examining the changing ideology of public health, shifting notions of health citizenship and voluntary/state welfare during this period.

In her 2007 book *Marketing Health: Smoking and the Discourse of Public Health, 1945–2000*, British historian Virginia Berridge used the ‘tracer policy’ of smoking to examine the

⁵⁷ Mauck, p.197. The ADA was a physician-only organisation until 1970 leading Greene to describe it as paternalistic: Greene, pp.87–88.

changing ‘ideology and outlook’ of public health and how this ‘meshed with changes in policy’ in Britain in the second half of the twentieth century.⁵⁸ Berridge argued that during this period there was a trend towards government regulation of lifestyle, which stemmed from the new importance of chronic diseases and the development of risk factor epidemiology to explain their aetiology.⁵⁹ The social sciences – such as psychology and health economics – also became important to public health. In the 1970s a new style of public health activism, characterised by single-issue organisations that used science-based campaigns and the mass media, brought lifestyle and risk to the fore. This development, Berridge explained, also stimulated new ‘policy communities’ of pressure groups and expert committees that sought ‘to bring science into closer relationship with policy-making’.⁶⁰ These trends evolved in parallel with the rise of ‘evidence-based medicine’ and the technocratic management of public health, which focused on more effective and efficient use of health resources. At an international level, a health promotion and primary care movement developed over the 1970s and 1980s that ‘began to stress the environmental and structural determinants of health’, while a new environmentalism in Britain emphasised individuals protecting themselves from risk.⁶¹

Increasingly, smoking became a behaviour of lower socio-economic groups and Berridge

⁵⁸ Berridge, *Marketing Health*, p.1. See also Virginia Berridge, ‘Post-war smoking policy in the UK and the redefinition of public health’, *Twentieth Century British History*, 14, 1, 2003, pp.61–82; and Virginia Berridge, ‘The policy response to the smoking and lung cancer connection in the 1950s and 1960s’, *Historical Journal*, 49, 4, 2006, pp.1185–209.

⁵⁹ On the United States context, where the insurance industry played a key role in developing risk factor thinking prior to chronic disease epidemiology, see William G. Rothstein, *Public Health and the Risk Factor: A History of an Uneven Medical Revolution*, Rochester, 2003. For more on the development of risk factor epidemiology and its incorporation into public health and clinical practice, see Robert Aronowitz, *Making Sense of Illness, Science, Society and Disease*, Cambridge, 1998; Luc Berlivet, ‘Association or Causation? The Debate on the Scientific Status of Risk Factor Epidemiology, 1947–c.1965’, in Virginia Berridge, ed., *Making Health Policy: Networks in Research and Policy after 1945*, Amsterdam, 2005, pp.39–74; Todd M. Olszewski, ‘The causal conundrum: the diet-heart debates and the management of uncertainty in American medicine’, *Journal of the History of Medicine and Allied Sciences*, 5 March 2014, doi: 10.1093/jhmas/jru001 (online advanced access); Dorothy Porter, *Health Citizenship: Essays in Social Medicine and Biomedical Politics*, Berkeley 2011, pp.154–220; and Frances Steel, ‘A source of our wealth, yet adverse to our health? Butter and the diet-heart link in New Zealand to c.1990’, *Social History of Medicine*, 18, 3, 2005, pp.179–94.

⁶⁰ Berridge, *Marketing Health*, pp.15–16; Virginia Berridge, ‘Issue Network versus Producer Network? ASH, the Tobacco Products Research Trust and UK Smoking Policy’, in Berridge, ed., *Making Health Policy*, pp.101–24.

⁶¹ Berridge, *Marketing Health*, p.17; Virginia Berridge, ‘Historical and Policy Approaches’, in Margaret Thorogood and Yolande Coombes, eds, *Evaluating Health Promotion: Practice and Methods*, 3rd edition, Oxford, 2010, pp.11–22.

posited that government-subsidised nicotine replacement therapy in the 1990s was an example of what she termed ‘pharmaceutical public health’: ““magic bullets” for social as well as individual behavioural problems’.⁶² Throughout these transitions, individual behaviour remained the predominant focus of post-war public health.

Diabetes is important to examine in relation to these changes. Diabetes was one of the earliest conditions subject to risk-factor epidemiology, with a prospective study in Oxford Massachusetts that began in 1946, and the more famous Framingham heart study identified diabetes itself as a risk factor for heart disease in 1961.⁶³ Although increasingly connected to lifestyle factors, the aetiological complexity and two distinct types of diabetes complicated a straightforward replication of approaches to smoking and lung cancer, such as occurred for dietary fats and heart disease, particularly as the more common form enjoyed a reputation as ‘mild’. In his thesis on diabetes management in Britain, Moore extended Berridge’s arguments about risk in public health to examine ‘how risk was handled in the clinic’.⁶⁴ That is, how doctors and the government came to not only use the media to educate the public on risk, but to use clinical spaces to identify at-risk patients and provide interventions. This was the basic idea of disease management, which came to dominate approaches to diabetes in Britain and the United States in the 1990s, and this thesis documents New Zealand’s experience in relation to these trends. In any case, individual lifestyle was at the crux of both clinical and educational configurations of public health. However, as Berridge also highlighted, there were multiple levels of policy influence and ideological outlook. This thesis considers the ways single-issue campaigning, health promotion, environmental and evidence-

⁶² Berridge, *Marketing Health*, p.2.

⁶³ Hugh Wilkerson and Leo Krall, ‘Diabetes in a New England town’, *Journal of the American Medical Association*, 135, 4, 1947, pp.209–16; Tattersall, pp.184–5.

⁶⁴ Moore, p.31.

based approaches influenced responses to diabetes in New Zealand in the second half of the twentieth century, while supporting the predominant focus on lifestyle.

Over the last two decades, public health historian Dorothy Porter has analysed this scientifically-legitimated focus on individual lifestyle and its relationship to notions of health citizenship in Western democratic societies. Porter defined health citizenship as the social contract between a state and its citizens for the protection and maintenance of health. This, she pointed out, has always entailed both rights and obligations that ‘oscillated and changed focus’ at different points in time.⁶⁵ For example, Porter described how in the mid-twentieth century, chronic disease and ageing populations contributed to political pressures to find ways to reduce health care costs which, by the end of the century, ‘transformed personal wellness into an individual contribution to the commonwealth’. This transformation was bolstered by a commercialised culture obsessed with ‘the healthy body’.⁶⁶ Yet, as Porter argued in her study of the contemporary history of the obesity epidemic, the focus on lifestyle disease prevention had not diminished government responsibility for controlling environments in the social contract of health. Porter suggested the ‘political quagmire’ of what this intervention would entail, however, meant few governments were prepared to act, while citizen-activists and citizen-consumers had begun to refashion the social contract of health with the food industry.⁶⁷ As diabetes came to be considered a chronic condition that was rising in concert with the ageing and fattening of the New Zealand population, Porter’s insights have a direct bearing on a central issue explored in this thesis: how assumptions about citizenship rights and responsibilities in population health informed responses to diabetes.

⁶⁵ Porter, *Health Citizenship*, p.2.

⁶⁶ *Ibid.*, pp.2, 65–83.

⁶⁷ Dorothy Porter, ‘The Social Contract of Health in the Twentieth and Twenty-First Centuries: Individuals, Corporations and the State’, in Susan Gross Solomon, Lion Murrard, and Patrick Zylberman, eds, *Shifting Boundaries of Public Health: Europe in the Twentieth Century*, New York, 2008, p.56

New Zealand social policy historian Michael Belgrave has argued that in order to understand approaches to health in any particular period, we need to examine changes in health risks and health technology in relation to governments' wider social policy objectives and the values which underpinned them.⁶⁸ In his formulation, the early twentieth century saw a transition from the overriding focus on self-reliance of the previous century to the need to strengthen the 'race', which was demonstrated in the expansion of public health services, particularly for children and mothers. From the late 1930s to the 1950s, the prime objective of social policy was to secure healthy families, which influenced the development of a universal health service and policies such as state housing and food subsidies. Individual citizenship rights gained greater prominence in the 1960s and an emphasis on access to personal health services, participation and, by the late 1970s, choice. Individual citizenship rights morphed into a policy objective of promoting consumer choice from the mid-1980s to meet an understanding of differentiated social need. This shift had its full expression in the market-oriented health reforms of the 1990s. Although Belgrave ascribed these objectives to distinct chronological periods, he also noted that there were sufficient overlaps to create continuities and contradictions through New Zealand's well-known short, sharp periods of reform under the first Labour government (1935–1949), which introduced the universal welfare state, and the retreat to a targeted residualist welfare system under the fourth Labour government (1984–1990) and fourth National government (1990–1999).⁶⁹ In line with Belgrave's arguments, this thesis pays particular attention not just to changing techniques of public health, but to governments' social policy objectives in order to illuminate why particular approaches to diabetes gained support, or otherwise, at various times.

⁶⁸ Michael Belgrave, 'A Historical Perspective on the Politics of Health Care', in Kevin Dew and Anna Matheson, eds, *Understanding Health Inequalities in Aotearoa New Zealand*, Dunedin, 2008, pp.69–84.

⁶⁹ Michael Belgrave, 'Needs and the State: Evolving Social Policy in New Zealand History', in Bronwyn Dalley and Margaret Tennant, eds, *Past Judgement: Social Policy in New Zealand History*, Wellington, 2004, pp.23–38.

These general trends in health citizenship and approaches to public health acquire different meaning from the standpoint of policies aimed at indigenous populations. In a 2008 article, Linda Bryder used New Zealand's phases of health citizenship for its indigenous people to look at why a policy introduced in 2000, which aimed at 'Closing the Gaps' between Maori and Pakeha (European New Zealanders) in health status, provoked a political and public furore.⁷⁰ Concern about, and attempts to address health inequalities between Maori and Pakeha were not new, but the response was. Bryder attributed this to developments since the transition from an 'integration' to a 'self-determination' phase of health citizenship in the late 1970s. To Maori activists of the late twentieth century, health citizenship meant 'not equality of access to health care, but equality of health status', which meant 'affirmative and targeted public health programmes' and Maori responsibility for Maori health.⁷¹ Such a goal emerged at the same time as the 'rolling back of the State' in welfare provision, which led to the government devolving responsibility for Maori health services to Maori providers. These contributed to the political backlash to 'Closing the Gaps' in which some perceived Maori as having become 'privileged citizens' in social policy, while some Maori saw dangers in the potential for stigmatisation of Maori as "“diseased” by virtue of being Maori".⁷² As epidemiology identified Maori as a foremost 'at-risk' group for diabetes by the late twentieth century, such issues are an important element in considering the shifting public perceptions and approaches to diabetes in New Zealand.

⁷⁰ Linda Bryder, 'Health Citizenship and "Closing the Gaps": Maori and Health Policy', in Astri Andersen, Tore Gronlie, William Hubbard, Teemu Ryyman and Svein Atle Skalevag, eds, *Citizens, Courtrooms and Crossings: Conference Proceedings*, Bergen, 2008, pp.51–61.

⁷¹ *Ibid.*, p.58.

⁷² *Ibid.* The issue of stigmatisation informed both Maori and health officials' responses to specific diseases which had higher rates among Maori than Pakeha in the latter twentieth century. See also Deborah Ann Dunsford, "“Seeking the Prize of Eradication”: A Social History of Tuberculosis in New Zealand from World War Two to the 1970s', PhD thesis, University of Auckland, 2008; and Deborah Mary Jowitt, 'Government Policy Relating to Hepatitis B in New Zealand 1970–2005', PhD thesis, University of Auckland, 2010.

In part a reflection of the changed political landscape at the end of the twentieth century, historians have turned from a traditional focus on state actions in social policy to the history of the ‘mixed economy of welfare’ or ‘welfare pluralism’— of private and voluntary provision as well as that of government. In the New Zealand context, Bryder in her work on the infant welfare organisation Plunket, and Margaret Tennant in her general examination of voluntary welfare, challenged both assumptions about the all-encompassing role of the state in the mid-twentieth century, and that voluntary responses were simply plugs to fill needs not met by the state.⁷³ Their accounts highlight more complex motivations and relationships between voluntary organisations and government at this time, including a prevailing public and political appeal of self-help. The government provided increasing levels of funding to voluntary organisations over the 1940s to 1970s, but Tennant argued that interactions were often ‘symbiotic’ and went ‘beyond the financial, involving a close identity of purpose, goals and even personnel’.⁷⁴

By the mid-1980s state/voluntary sector relationships entered a new era, which Tennant dubbed the ‘Contract Crunch’. Government increasingly formalised relationships with voluntary organisations in contracts by setting out quantifiable ‘outputs’ for service delivery. Government contracts brought an array of questions about the roles and responsibilities of actors in the health and welfare space, which continue in debates today, but as Tennant has argued ‘boundaries have always been permeable’.⁷⁵ As already indicated, diabetes associations, with their objective to promote the welfare of people with diabetes, are a key

⁷³ Margaret Tennant, ‘Mixed Economy or Moving Frontier? Welfare, the Voluntary Sector and Government’, in Dalley and Tennant, pp.39–56; Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, Wellington, 2007; Linda Bryder, ‘Plunket’s Secret Army’: The Royal New Zealand Plunket Society and the State’, in Dalley and Tennant, pp.109–24; Linda Bryder, *A Voice for Mothers: The Plunket Society and Infant Welfare, 1907–2000*, Auckland, 2003.

⁷⁴ Margaret Tennant, ‘Two to tango: the partnership between charity and the welfare state in New Zealand 1940–1970’, *New Zealand Journal of History*, 42, 1, 2008, p.17.

⁷⁵ Tennant, ‘Mixed Economy or Moving Frontier?’, p.55. Virginia Berridge and Alex Mold deal with these issues in the British context in *Voluntary Action and Illegal Drugs: Health and Society in Britain since the 1960s*, Basingstoke, 2010.

focus of this thesis. Following the trend of examining voluntary welfare, and the relationship of voluntary organisations with government, this study uses Tennant's framework to emphasise the ways social policy concerns interacted with public health approaches to diabetes in New Zealand in the twentieth century.

Chapter Outline

Taking a broadly chronological approach, this thesis charts the development of public health concerns about diabetes in New Zealand, and the responses. Chapter One describes the emergence of epidemiological interest in diabetes in New Zealand from statistical analyses like McNickle's in the 1920s to major, transnational, chronic disease studies, begun in the 1960s and concluded in 1982, which documented the significantly higher prevalence of diabetes in Maori and Pacific groups compared to Pakeha. It asks how researchers made sense of diabetes in New Zealand and what the implications of their explanations were to have for subsequent public health interventions.

Chapters Two to Four focus on the relationship between local diabetes societies and public health initiatives during the period of the classic welfare state. Chapter Two discusses the establishment and roles of diabetes societies in New Zealand from their instigation during the Second World War and their connections to concerns about social welfare and health citizenship. Through an examination of their major activities, it interrogates the relationships between health professionals and people with diabetes, and voluntary organisations and government. Chapter Three extends the exploration of these relationships within the public health campaigns to find 'hidden diabetics' in the 1960s. Placing detection drives within a broader discussion of disease screening, it examines the factors that influenced these campaigns up to the 1980s. Chapter Four turns to the development of the diabetes education

movement in the 1970s and 1980s that aimed to improve ‘patient self-sufficiency’ and thus reduce hospitalisations and diabetes complications. Through focusing on the role of consumer groups and non-medical health professionals, these chapters question social control interpretations of these aspects of diabetes management.

Chapters Five to Seven focus on the approaches to diabetes in the 1980s and 1990s under governments that had a more limited vision of the role of the welfare state and that faced economic constraints. Chapter Five considers how both professional and consumer organisations, led by New Zealand’s widely regarded ‘father of diabetes’ and self-described ‘ageing activist’, Professor (later Sir) Donald Beavan, attempted to politicise, gain resources for, and change the public image of diabetes in the 1980s.⁷⁶ Chapter Six examines the changing relationship between the voluntary sector and the state in the 1990s and the impact of social policy changes on people with diabetes. It investigates how and why the government of the day, which was intent on cutting health and welfare spending generally, came to fund a major diabetes management plan in 1999. It also documents the emergence of a new, less politically appealing, public health understanding of what became known as the ‘obesogenic environment’. Chapter Seven picks up a key theme in these developments of the 1980s and 1990s, that many Maori and Pacific people were not well served by, and did not want, mainstream health services. Focusing on South Auckland, an area with a high proportion of Maori and Pacific people, it explores the interplay between international public health movements, national politics and community activism in developing a distinctive approach to diabetes. These chapters explore the appeal and effectiveness of diabetes interventions aimed at empowering individuals and at-risk communities against the wider socio-economic changes of the late twentieth century.

⁷⁶ Flora Davidson to Beavan, 17 January 1979, D.W. Beavan Papers Accession #195, 36755, Macmillan Brown Library, Canterbury (MBL).

Taken together these chapters underscore the social and political value of the ideology of ‘self-sufficiency’ in mid to late twentieth-century New Zealand, and its limitations. As such, this thesis contributes not only another case study in the history of diabetes management, but to broader themes in the history of public health and social policy in this period.

CHAPTER ONE

‘The price of civilization’: diabetes epidemiology and the emergence of a public health problem c.1920–1982

The impact of civilization on the inhabitants of the islands in the broad Pacific has usually been something less than beneficial, historians tell us... [of] an almost fatal impact on the islanders’ idyllic way of life until some once serene spots in the Pacific can hardly be distinguished from the cities of America and Europe.... In fact, it does not seem too much to say our evidence now shows that the farther the Pacific natives move from the quiet, carefree lives of their ancestors, the closer they come to gout, diabetes, atherosclerosis, obesity, and hypertension.¹

As historians were reinterpreting the grand narrative of medicine and colonialism from one of benevolence to fatal impact in the 1970s, epidemiologists were documenting a similar contemporary process. The ‘killing disorders of Western societies’ – the diseases of ‘affluence’ – were now also becoming the killing disorders of indigenous and developing populations.² It appeared death and disease continued to be the ‘the price of civilization’. The passage quoted above comes from a 1971 article in which Dr Ian Prior, often credited as ‘New Zealand’s founder of modern epidemiology’, discussed his ongoing research into diabetes in New Zealand and the Pacific.³ Several decades earlier, the *Christchurch Sun* reported the ‘opinion of most doctors’: that a growing incidence of diabetes ‘throughout the civilised world’ was ‘the result of an increasedly [sic] artificial method of living ... in the output of nervous energy, of the strain of modern life, and of an increasing disproportion between the amount of food consumed and the amount of exercise taken’.⁴ This interpretation, that rising rates of diabetes were a consequence of the advance of societies, held considerable explanatory power for much of the twentieth century.

¹ Ian A.M. Prior, ‘The price of civilization’, *Nutrition Today*, July/August 1971, pp.2–11.

² I.A.M. Prior, ‘Polynesian Health: Planning for Success’, in D.W. Beaven and B.H. Easton, eds, *The Future of New Zealand Medicine: A Progressive View*, Christchurch, 1974, p.111.

³ Ian Prior, Philippa Howden-Chapman and Alastair Woodward, eds, *The Health of Pacific Societies: Ian Prior’s Life and Work: A Celebration at the Wellington School of Medicine 25 February 2000*, Wellington, 2001, p.47.

⁴ ‘Suggestion not borne out by medical views’, *Christchurch Sun*, 28 April 1934.

Yet, diabetes did not provoke much public health concern until the second half of the twentieth century in New Zealand. In his doctoral dissertation on the history of diabetes management in the United States, Aaron Mauck discussed how diabetes posed particular difficulties for contemporaries trying to understand the greater prominence of the disorder in the early twentieth century. He went on to highlight the important contribution of new epidemiological techniques in determining a hidden diabetes problem in the post-World War Two era.⁵ By the 1960s, as Stephanie Stegman's doctoral dissertation on diabetes in the American Southwest illuminated, community-based surveys found much higher rates of diabetes in indigenous groups than in the rest of the population. Researchers saw these communities as 'natural experiments': opportunities to study the aetiology of diabetes and its complications, which Stegman argued also brought wider recognition to a public health crisis.⁶ Building on this work, this chapter examines the evolution of epidemiological interest in diabetes in New Zealand from early statistical analyses in the 1920s through to Prior's major population studies of the 1960s and 1970s. It traces how researchers and other observers made sense of diabetes' apparent increase and what their explanations meant for understandings of, and responses to, diabetes as an emerging public health problem in New Zealand.

'It would appear diabetes presents a serious and growing public problem'

In his 1934 annual report to the North Canterbury Hospital Board, Medical Superintendent Dr W. Fox commented that 'the incidence of diabetes has increased markedly ... during the last 15 to 20 years.... it would appear diabetes presents a serious and growing public problem'.⁷

Fox was not alone in his assertion that diabetes was on the rise in New Zealand in the early

⁵ Aaron Pascal Mauck, 'Managing Care: The History of Diabetes Management in Twentieth Century America', PhD dissertation, Harvard University, 2010, pp.136–91.

⁶ Stephanie Stegman, 'Taking Control: Fifty Years of Diabetes in the American Southwest 1940-1990', PhD dissertation, Arizona State University, 2010, pp.23–119.

⁷ 'Diabetes', *Christchurch Times*, 27 April 1934.

twentieth century, as medical students, physicians and health officials grappled with statistics and speculated on what may have caused the increase. Nor was New Zealand alone in seeing more diabetes.

In the Western world, medical professionals became much more aware of diabetes with developments in diagnosis and treatment in the early twentieth century. Scientific medicine was in the ascendency, seen in the growing importance of the laboratory, the hospital as a site of treatment rather than place for the care of the poor, and increasing medical specialisation. Laboratory technologies and treatment protocols created and enabled complex analyses and monitoring of patient urine, blood, and quantitative dietary management.⁸ Although doctors usually diagnosed diabetes by symptoms and the presence of sugar in the urine, the 1910s saw the development of a new diagnostic tool, the glucose tolerance test, which measured sugar in the blood following the ingestion of a glucose load.⁹ Moreover, as Mauck has explained, because the new diabetes specialists developed hospital clinics in the 1900s and 1910s, they were able to concentrate a sizeable patient population and therefore they had unprecedented opportunities for clinical teaching and research. This had significant outcomes for treatment. For example, at the Rockefeller Institute Hospital in New York, Dr Frederick Allen developed his systematic programme of under-nutrition, the ‘Allen treatment’, in the 1910s.¹⁰

Boston physician Elliott Proctor Joslin detailed his early success with such starvation diets in his 1916 textbook, *The Treatment of Diabetes Mellitus*, and expanded on it in a second edition two years later. The textbook was an anthology on every aspect of clinical knowledge about diabetes derived from his treatment of nearly 1000 diabetes patients. Joslin was regarded as

⁸ Mauck, p.124.

⁹ Robert Tattersall, *Diabetes: The Biography*, Oxford, 2009, pp.180–3.

¹⁰ F.M. Allen, E. Stillman and R. Fitz, *Total Dietary Regulation in the Treatment of Diabetes*, New York, 1919. On the British experience, see Martin D. Moore, ‘A Question of Control? Managing Diabetes and Its Professionals, 1910–1994’, PhD thesis, University of Warwick, 2014, pp.68–75.

the preeminent diabetes specialist of the first half of the twentieth century and certainly, through his textbooks, he was very influential on New Zealand medical students' and professionals' understanding of the disorder.¹¹ Joslin labelled the period 1914 to 1922 the 'Allen Era', indicating the significance of the therapeutic development.¹²

In New Zealand, this therapeutic development motivated John William Hall to make the first statistical study of the country's diabetes mortality rates for his Doctor of Medicine thesis in 1920. Hall explained his aim was to see 'whether the disease is sufficiently prevalent in New Zealand to justify the establishment of a clinic at the Dunedin Hospital for the instruction of medical students in the Allen treatment, and for the benefit of diabetics'.¹³ Hall noted numerous problems with the quality of statistics available but still reported 'an enormous increase' which had 'been steady and practically continuous' in the number of deaths from diabetes between 1872 and 1918.¹⁴ His analysis suggested that the significant factors behind this increase were better diagnosis with more medical practitioners in the country and the wider statistical effects of New Zealand's low infant mortality rate.¹⁵ Hall noted that diabetes did not feature strongly in public hospital statistics as many people with the disease were treated at home, but that there were enough good 'candidates for possible success under the Allen treatment' to justify the establishment of a clinic.¹⁶

It was the discovery of an even more effective treatment – insulin – that encouraged New Zealand's main public hospitals to establish specialised clinics or wards for diabetes.

¹¹ Tattersall, p.49.

¹² For more on the Allen treatment and physician, public and patient responses to it, see Mauck, pp.88–93; and Tattersall, pp.46–51.

¹³ John William Hall, 'An Inquiry into the Mortality from Diabetes Mellitus in New Zealand along with Some Observations and Remarks on the Allen Treatment of Diabetes Mellitus', MD thesis, University of New Zealand (Otago), 1920, p.1.

¹⁴ *Ibid.*, p.8.

¹⁵ *Ibid.*, p.25.

¹⁶ *Ibid.*

Heralded as one of the greatest medical advances of the early twentieth century, over 1921 to 1922 researchers at the University of Toronto produced the first useful and consistent preparation of injectable insulin, a hormone created in the pancreas, which could treat diabetes. Insulin's ability to bring back young patients from the brink of death led to much optimism that it might even cure the disease, which greatly expanded the medical and media awareness of diabetes.¹⁷ Doctors held equal hope for older cases too, as they generally viewed diabetes as a single disease entity differentiated by the degree of severity of symptoms, often connected to age.¹⁸ Within a few years most understood that insulin was no cure, but it still transformed the prognosis for people with diabetes and the nature of diabetes therapy. In New Zealand, a small number of physicians interested in diabetes began establishing diabetes clinics or wards in the larger hospitals where they refined the use of insulin on diabetes patients.¹⁹ From the 1920s to 1940s New Zealand doctors' interest in diabetes was largely one of therapeutic management as they reported on their experiences with insulin and dietary treatment to the wider medical community in New Zealand.²⁰

¹⁷ Elliot P. Joslin, *The Treatment of Diabetes Mellitus: With Observations Based upon Three Thousand Cases*, 3rd edition, London, 1924, p.110. For a succinct summary of the arrival of insulin treatment, see Tattersall, pp.52–58.

¹⁸ Mauck, pp.19–21.

¹⁹ M.H. Watson, 'The early days of insulin in New Zealand', *New Zealand Medical Journal* (NZMJ), 93, 684, 27 May 1981, pp.347–8. Donald McDonald Wilson, *A Hundred Years of Healing: Wellington Hospital, 1847–1947*, Wellington, 1948, p.70. 'Diabetic departments' or clinics appeared in the 1930s.

²⁰ C.R. Burns, 'Diabetic coma – some points of interest illustrated by recent cases', NZMJ, 27, 137, February 1928, pp.9–18; C.R. Burns, 'Treatment of diabetes mellitus', NZMJ, 31, 165, October 1932, pp.342–9; C.R. Burns, 'The "high carbohydrate diet" in the treatment of diabetes', NZMJ, 35, 190, 1936, pp.377–86; C.R. Burns, 'A note on the use of protamine insulin in the treatment of diabetes', NZMJ, 36, 192, December 1936, p.130; D.M. Wilson, 'Treatment of glycosuria in Toronto General Hospital', NZMJ, 22, 1923, pp.267–77; H. Bayldon Ewen, 'Insulin in the treatment of diabetes', NZMJ, 25, 128, August 1926, pp.187–202; K.J.L. Scott, 'Clinical observations on diabetes', NZMJ, 23, 1924, pp.147–56; H. Bayldon Ewen, 'Coma – hyperglycaemic and hypoglycaemic – notes on some unusual cases', NZMJ, 23, 1924, pp.480–4; W.P.P. Gordon and Doris C. Gordon, 'Interruption of insulin treatment without ill effects', NZMJ, 23, 1924, pp.408–10; H. Bayldon Ewen, 'The danger of interruption of insulin treatment', NZMJ, 23, 1924, pp.257–9; J.M. Twigg, 'Experiences with zinc protamine insulin', NZMJ, 37, 201, October 1938, pp.246–63; Wilton Henley, 'Some endocrine inter-relationships in diabetes mellitus; a report of experimental results obtained with oestrin in a case of insulin resistant glycosuria', NZMJ, 39, 214, December 1940, pp.308–26; R.R.D. Milligan, 'Severe insulin allergy: report of a case', NZMJ, 40, 220, December 1941, pp.383–4; See also letters to the editor regarding experiences with protamine zinc insulin: R.R.D. Milligan, NZMJ, 41, 222, April 1942, pp.114–16; Charles Burns, NZMJ, 41, 223, June 1942, pp.143–4; W.S. Charles, NZMJ, 41, 223, June 1942, pp.144–5.

With the introduction of insulin some began to consider its implications for diabetes statistics. In 1924 Robert Roy Milligan, the first biochemist at Christchurch Hospital, demonstrated the early optimism about insulin in a speech to the Canterbury Philosophical Institute. Milligan argued that thanks to insulin, 'Next year, probably, there would be a tremendous drop in the death rate from diabetes and in a few years there might be no deaths from diabetes in the Dominion.'²¹ In 1925 the Director-General of Health, Dr Thomas Valintine, requested the Government Statistician provide him with the number of deaths from diabetes in 1924 'in view of investigations now in hand relating to treatment with insulin'.²² Clearly, some doctors and health officials expected the key measure of the public's health, mortality rates, to reflect the apparent magnitude of the therapeutic breakthrough of insulin.

It was during this time of enthusiasm about insulin, in 1925, that the *New Zealand Medical Journal* (NZMJ) published the first statistical study of diabetes mortality in New Zealand. Dr L.C. McNickle, a future Director of the Health Department's Hospitals Division, listed the number of deaths from diabetes in the non-Maori population, from the earliest to the most recently available figures in the *Official Yearbook* (1872–1922). He found the death rate rose from 0.11 per 10,000 of mean population in the first five years to 1.42 in the last five years under consideration. Although these statistics could not show the impact of insulin, McNickle believed that, with the improved prognosis since the introduction of the Allen treatment, the recent increase in deaths was 'definite and alarming'.²³ Particularly, as McNickle explained, the figures elided those who died from other conditions to which people with diabetes were more susceptible, such as arteriosclerosis and tuberculosis. McNickle argued that although little at that time was known about the aetiology of the disease, his experience studying sixty

²¹ 'Insulin cure', *Lyttleton Times*, 7 August 1924.

²² Valintine to Government Statistician, 1 April 1925, Diabetes 1922–41, ADBZ 16163 H 1 1364 131/20 (13393), Archives New Zealand, Wellington (ANZW).

²³ L.C. McNickle, 'Diabetes in New Zealand – discussed etiologically', NZMJ, 24, 1925, p.244.

diabetes patients suggested to him that obesity and overfeeding were ‘the most obvious, the most important, and the most remedial cause’.²⁴ He asserted that, ‘as an essentially preventable disease, it [was] ... time something was done to prevent it’ and called on doctors to educate the public on symptoms so they might seek early diagnosis and avoid obesity.²⁵

McNickle’s study was the earliest example of the argument that diabetes was a preventable public health problem in New Zealand. Even in the United States, which had probably the highest and most scrutinised death rates from diabetes in the world at that time, such an argument was rare. Joslin is usually attributed as being the first to have called diabetes an ‘epidemic’; in a 1921 article entitled ‘The prevention of diabetes’ Joslin noted how six out of seven people in adjoining houses on one street in his hometown of Oxford Massachusetts had recently died of diabetes, yet ‘no one spoke of an epidemic’.²⁶ Had they died of typhoid or tuberculosis, Joslin argued, the health authorities would have sprung into action to discover the source of the disease. Epidemiology at that time almost exclusively focused on tracing the source and spread of infectious diseases. The variety of precipitating factors seen in individuals with diabetes made it difficult to accept a single correlated association. Based on clinical experience, obesity appeared to be the most significant aetiological factor. However, as McNickle acknowledged, for a number of cases it seemed unfair to posit the cause of their disease as excessive eating and, indeed, he put his own development of the disorder down to ‘neurotic tendencies’.²⁷ With the development of bacteriological thinking, many believed infection might be responsible for the rise in diabetes. In 1925 the New Zealand Minister of Health even requested for ‘a bacteriological examination of the stools’ of all diabetes patients treated at Wellington Hospital to determine ‘whether or not some specific organism, or

²⁴ Ibid., pp.250–1.

²⁵ Ibid., p.245.

²⁶ E.P. Joslin, ‘The prevention of diabetes’, *Journal of the American Medical Association*, 76, 1921, p.79.

²⁷ McNickle, pp.247, 250.

organisms, is associated with the causation of the increasing number of diabetes cases being reported in New Zealand'.²⁸ McNickle's article highlighted the problem contemporaries faced in trying to explain rising rates of a disease with apparently multiple causes.

Many did not perceive the increase in diabetes as a public health problem, but as a positive effect of medical advances. In 1934 two medical students at the University of Otago extended Hall's 1920 investigation of diabetes mortality to consider the impact of the availability of insulin. They found that while death rates in children had decreased, mortality in older age groups had continued to rise. This, they argued, was a statistical effect of insulin lengthening the lives of younger people with diabetes. Additionally, they suggested insulin was allowing people with diabetes 'to reach an age where death from degenerative conditions is relatively common'.²⁹ At this point most understood heart disease and arteriosclerosis, now known to be long-term complications of diabetes, as having no causal link to diabetes; their increase was thought to be a result of increasing age. The students attributed the fact that there were more deaths and discharges from New Zealand hospitals for diabetes since Hall's investigation, to improved diagnosis, record keeping and 'the stimulus to medical interest generally, evoked by the advent of such aid to treatment as insulin'.³⁰ More hospitalisations occurred precisely because there was a more effective treatment, administered in hospitals, while greater survival meant more complications and multiple admissions. The Health Department concurred in 1943: the 'comforting' increase in diabetes was a consequence of insulin lengthening the lives of people with diabetes.³¹

²⁸ Valentine to the Bacteriologist, Wellington Hospital, 24 November 1925, ADBZ 16163 H 1 1364 131/20 (13393), ANZW; Tattersall, p.32. On the development of bacteriological thinking in New Zealand, see Katrina Ford, 'The Tyranny of the Microbe: Microbial Mentalities in New Zealand, c.1880–1915', PhD thesis, University of Auckland, 2013.

²⁹ 'A Study of the Morbidity and Mortality from Diabetes Mellitus in New Zealand, 1918–1933', Preventive Medicine Dissertation, University of Otago, 1934, p.8. The University of Otago Library requests anonymous citation of dissertations in this collection.

³⁰ *Ibid.*, p.16.

³¹ 'Diabetes cases', *Auckland Star*, 26 February 1943.

Diabetes had been long understood as having a heredity component, so some believed the increase in diabetes might also have occurred as insulin allowed more people with diabetes to reproduce. In the nineteenth century, physicians typically classified diabetes as a constitutional disease with a hereditary mode of transmission.³² European diabetes specialists reported around a quarter of their patients had other family members affected.³³ Presumably, people who developed diabetes later in life had passed on their hereditary predisposition during their reproductive years as, prior to insulin treatment, people with juvenile diabetes rarely survived long enough to have children, and the Allen treatment of undernourishment typically left young women infertile. The few documented cases of diabetic pregnancy in the nineteenth century largely ended in maternal and foetal death. If diabetes first appeared during pregnancy, what is now known as gestational diabetes, the woman was more likely to survive, but foetal or neonatal death was still common.³⁴ The Otago medical students who conducted the 1934 statistical analysis speculated that there were more ‘congenital’ cases of diabetes now as insulin ‘has allowed many children of diabetics to be born who otherwise would not have been’ and that more work was needed to understand ‘the mechanism by which diabetes is transferred from one generation to another’.³⁵ As hereditary explanations evolved into the field of human genetics in the early twentieth century, researchers tried to fit diabetes into the Mendelian dominant/recessive rules of inheritance. In the 1930s Gregory Pincus and Priscilla White’s investigations at the Joslin clinic popularised a simple autosomal recessive

³² Donald M. Barnett and Leo P. Krall, ‘The History of Diabetes’, in C. Ronald Kahn, Gordon C. Weir, George L. King, Alan C. Moses, Robert J. Smith and Alan M. Jacobsen, eds, *Joslin’s Diabetes Mellitus*, 14th edition, Boston, 2005, p.10. For more on the overlapping influences of heredity and infection transmission theories on medical research, practices, policies, see Jean-Paul Gaudillière and Ilana Löwry, eds, *Heredity and Infection: The History of Disease Transmission*, London, 2001.

³³ Tattersall, p.189.

³⁴ For more on the history of the management of diabetes in pregnancy, see Chris Feudtner, *Bittersweet: Diabetes, Insulin and the Transformation of Illness*, Chapel Hill, 2003, pp.146–68.

³⁵ ‘A Study of the Morbidity and Mortality from Diabetes Mellitus in New Zealand, 1918–1933’, p.23.

inheritance.³⁶ Not universally accepted, however, other researchers continued searching and suggesting alternative inheritance patterns. This search for a genetic explanation was unsuccessful as researchers assumed a single gene was responsible for the susceptibility to diabetes, in all its forms, and because of a dearth of family histories.³⁷

Doctors and public health advocates sometimes questioned whether people with diabetes should reproduce at a time when eugenic thought ran high in many Western countries. However, eugenic solutions were not popular in either the United States or New Zealand. Historian Arlene Tuchman argued that eugenic solutions did not gain much traction in the United States because of perceptions that people with diabetes were mostly white and middle or upper class and possessed socially valuable traits that outweighed the potential risk of passing on ‘defective’ genes.³⁸ In New Zealand, although some occasionally suggested people with diabetes should not marry other people with diabetes, more medical attention was focused on helping women with diabetes achieve successful pregnancies. Although the numbers of pregnant women with diabetes was still small, they experienced a foetal mortality rate of 55 per cent in the 1930s and 1940s. The babies of women with diabetes could suffer from congenital abnormalities and both live and stillborn babies were often oversized (over 4kg). Doctors began to recognise women who developed diabetes after childbearing tended to have had large babies – a sign of the woman’s ‘pre-diabetic state’.³⁹ The focus on improving outcomes for diabetic pregnancy most likely reflected the faith in scientific medicine and pronatalist social attitudes of the period.

³⁶ Tattersall, p.189.

³⁷ Ibid., p.191.

³⁸ Arleen Marcia Tuchman, ‘Diabetes and “defective” genes in the twentieth century United States’, *Journal of the History of Medicine and Allied Sciences*, 70, 1, January 2015, pp.1–33.

³⁹ W.E. Henley, ‘Diabetes and pregnancy’, *NZMJ*, 46, 255, 1947, pp.386–97. Henley went on to set up the first specialist diabetes in pregnancy clinic in New Zealand in the 1950s at National Women’s Hospital in Auckland.

This pronatalist climate was apparent in a lively discussion on diabetes potential precipitating factors that appeared in the local press following the release of Christchurch Hospital's annual report for 1933-34. In the report, the hospital's Medical Superintendent, Dr W. Fox, stated that there had been a marked increase in diabetes in recent years, particularly among women and children. When the North Canterbury Hospital Board considered Fox's report at their annual meeting in April 1934, Mrs J.A. Bean drew attention to the fact that the period of increase in diabetes coincided with the length of time the Plunket Society had been in operation. Founded in 1907, the Plunket Society was a highly regarded infant welfare voluntary organisation, which acquired significant political support in an era of concerns about national efficiency. Plunket advocated breastfeeding in the first instance, but when a mother was unable to breastfeed, it promoted a scientifically developed substitute as close as possible to a mother's natural milk.⁴⁰ Mr J.K. Archer questioned Mrs Bean, 'Surely you do not suggest that the Society is responsible?'⁴¹ Mrs Bean denied any criticism of Plunket but thought the correlation was worth investigating. In response Dr H.L. Widdowson, 'one of the medical men connected with the Plunket Society', argued in the *Christchurch Press* that the increase in diabetes was not unique to countries using the Plunket system.⁴² The consensus of doctors, as reported in the *Christchurch Sun*, was that the 'tendency to acquire diabetes was ... mainly an inherited one, and modern conditions of life, particularly among town dwellers, were an encouragement to the complaint'. Doctors reassured the New Zealand public that the statistical increase in diabetes was not because of how they fed their babies as it was increasing throughout the 'civilised world'.⁴³

⁴⁰ Linda Bryder, *A Voice for Mothers: the Plunket Society and Infant Welfare, 1907–2000*, Auckland, 2003.

⁴¹ 'Diabetes', *Christchurch Times*, 27 April 1934.

⁴² 'The Plunket system and diabetes', *Christchurch Press*, 30 April 1934.

⁴³ 'Suggestion not borne out by medical views'.

Since the turn of the century physicians had suggested diabetes was ‘one of the penalties of advanced civilization’.⁴⁴ English physician Robert Saundby made this comment in 1897 based on reports from British India, which noted diabetes was around seven times more common in the upper castes who had more Westernised diets and high-ranking government or office jobs, than in labourers and rural peoples.⁴⁵ Historian David Arnold has shown how both Western and Indian medical men espoused aetiological theories connected to class and racial ideologies that intersected with concerns about the stresses of modern life.⁴⁶ In Western countries diabetes appeared to follow affluence; in Europe diabetes cases were rare in public hospitals, which treated the poor and hungry.⁴⁷ In the United States, further evidence that diabetes was a problem of the wealthy urban elite was seen in statistical reports of a high prevalence of diabetes amongst Jews; Jewish people were typically educated, lived in the busy urban centres and were thought to have a tendency to overindulge in a traditional rich diet.⁴⁸ Characterisations of Jews as sensitive or neurotic, Tuchman has argued, also served as demonstrations of their high level of civility and thus proneness to diabetes.⁴⁹ Various aspects of civilised life – dietary overindulgence, an overly refined and high-sugar diet, lack of exercise, mental work or ‘nervous strain’ – supposedly could bring on diabetes. These factors, which Mauck has called ‘the pathogenic effects of urban life’, reflected commonplace health anxieties about urbanisation and the expansion of white-collar work in the early twentieth century.⁵⁰ Doctors’ interpretation of the statistics on diabetes at Christchurch Hospital highlighted these ‘pathogenic effects’, with Fox himself noting the increase was most likely

⁴⁴ Saundby quoted in Tattersall, p.178.

⁴⁵ Ibid, p.179; Gary Taubes, *Good Calories, Bad Calories: Fats, Carbs and the Controversial Science of Diet and Health*, New York, 2007, pp.102–3.

⁴⁶ David Arnold, ‘Diabetes in the tropics: race, place and class in India, 1880–1965’, *Social History of Medicine*, 22, 2, 2009, pp.245–61.

⁴⁷ Tattersall, p.178

⁴⁸ Mauck, p.141.

⁴⁹ Tuchman.

⁵⁰ Mauck, p.140. On the nineteenth century origins of these concerns, see Charles M. Rosenberg, ‘Pathologies of Progress: The Idea of Civilization as Risk’, in his *Our Present Complaint: American Medicine, Then and Now*, Baltimore, 2007, pp.77–85.

the result of improved standards of living, increasing mechanisation of labour and increased food intake: ‘This disease is not one of depression but probably of over-indulgence.’⁵¹

In 1948, another Otago medical student had made a statistical study of diabetes which estimated that New Zealand was on its way to leading the rest of the civilised world in its incidence of diabetes. The study presented figures that showed the diabetes death rate had doubled in the past twenty years and New Zealand came in a close second behind the United States. While the author admitted numerous problems with his statistical data, he argued this was mostly in the direction of underestimating the size of the population with diabetes. He considered all the factors Joslin used to explain the increase of diabetes in the United States to be relevant in New Zealand. These factors included better diagnosis and medical surveillance, population growth, urbanisation, more people living until their sixties (the commonest age of onset), young people with diabetes living longer and reproducing, and a more medically conscious public liable to seek these diagnoses. He also had made an analysis of diabetes cases at Auckland and Dunedin hospitals, which found 43 per cent of patients had a family history of the disease, 52 per cent of patients were overweight at diagnosis and a further 28 per cent had been overweight prior to diagnosis.⁵² The author suggested this supported Joslin’s aetiological argument that heredity determined susceptible individuals in which precipitating factors, the most important of which was obesity, brought on diabetes.⁵³ He, like Joslin, believed that health authorities, ‘should make a serious effort to make the foolish fat man or woman realise he is a candidate for diabetes’.⁵⁴

⁵¹ ‘Diabetes’, *Christchurch Times*, 27 April 1934.

⁵² ‘Some Public Health Aspects of Diabetes Mellitus’, Preventive Medicine Dissertation, University of Otago, 1948, pp.42, 45.

⁵³ Joslin, p.68.

⁵⁴ ‘Some Public Health Aspects of Diabetes Mellitus’, p.87.

In trying to establish the incidence of diabetes for this study, the student had found ‘Statistics in New Zealand on Diabetes Mellitus are practically non-existent.’⁵⁵ Official records often did not specify diabetes as the main cause of death, or even a contributing cause, particularly in older patients whose death from long-term complications might appear to be separate degenerative processes. In 1949 the international classification for causes of death changed, removing the option of listing contributory causes, which exacerbated the invisibility of diabetes public health impact in mortality statistics.⁵⁶ The student had unsuccessfully tried to get alternative statistics from the Health Department, armed forces and insurance companies.⁵⁷ He had considered the latter after reading statistical analyses that Joslin had made in conjunction with Metropolitan Life Insurance statisticians.

In the United States, the life insurance industry played a key role in statistical analyses of diabetes in the early twentieth century. From 1880 to 1920 there was exponential growth in the number of Americans holding life insurance policies in concert with the expanding industrial labour force.⁵⁸ More policyholders potentially meant more profits for the companies, if they could reflect mortality risk patterns in policy prices. This led to the collection of a range of health information from enrollees on pre-existing conditions, eventual cause of death, height, weight, and data from medical examinations, including the results of tests for urine sugar. As Mauck has explained, data from life insurers ‘could potentially identify physical characteristics or personal behaviours that correlated with the eventual onset of diabetic symptoms’.⁵⁹ One of these characteristics was being overweight and, in 1943,

⁵⁵ Ibid., p.10.

⁵⁶ Ibid., p.11. On the effects of the change in causes of death reporting on diabetes rates, see James Wright Presley, ‘A History of Diabetes Mellitus in the United States, 1880-1990’, PhD dissertation, University of Texas, 1991, pp.383–91.

⁵⁷ ‘Some Public Health Aspects of Diabetes Mellitus’, p.12.

⁵⁸ Mauck, p.147. For more on the contribution of the involvement of the life insurance industry in the early development of chronic disease epidemiology, see William G. Rothstein, *Public Health and the Risk Factor: A History of an Uneven Medical Revolution*, Rochester, 2003, pp.50–76.

⁵⁹ Mauck, pp.148–9.

Metropolitan Life introduced standard height-weight tables to help people determine their risk.

In New Zealand, the Health Department began advising the public about the dangers of being overweight in the early 1940s. As part of the Department's expanded health and nutrition education activities during the Second World War, nutritionist Dr Muriel Bell, and 'radio doctor' Dr Harold Turbott, broadcast and wrote a number of advice columns on the problem of fatness, particularly at middle age. Attempting to reduce rates of New Zealand's biggest killer, heart disease, they highlighted the extra strain obesity put on the heart but also often mentioned a link between obesity and diabetes.⁶⁰ The Department typically drew statistical evidence for this link from Metropolitan Life.

Reliance on overseas statistics was not surprising, as the Department lacked the statistical tools to determine the current, or future, extent of diabetes in the New Zealand population.

The Acting Government Statistician wrote to the Director-General of Health in 1946,

As neither the deaths nor the cases treated in hospital can be regarded as a fair sample of the diabetic population of New Zealand, I regret that it is not possible ... from these figures to establish the probable diabetic population in New Zealand in the future. This could only be done by taking a specific inquiry over a selected section of the population'.⁶¹

In 1958 the Health Department's statistician still had to respond to an overseas enquirer that it was 'not possible to calculate readily the true incidence of this disease' because private physicians diagnosed and treated many cases and hospital diabetes clinics treated patients 'as outpatients, and for this reason do not come into our public health statistics'.⁶²

⁶⁰ Courtney Harper, "'The Art of Eating, has in Fact, Become a Science": Dietary Advice from the Interwar Period to 1960', MA thesis, University of Auckland, 2008, pp.127–38.

⁶¹ G.E. Wood, Acting Government Statistician to C.A. Taylor, Director General of Health, 26 July 1946, Diseases – Allergic, Endocrine and Nutritional – Diabetes 1925–84, ABQU 632 W4452 15/ 5/4/3 (0844).

⁶² R.J. Rose to A. Reshef, 28 October 1958, ABQU 632 W4452 15/ 5/4/3 (0844), ANZW. While theoretically outpatients, patients needing insulin were admitted for 'stabilisation', as well as patients with complications.

Elsewhere, from the 1940s, there was growing suspicion that a large number of asymptomatic, undiagnosed, ‘hidden diabetics’ lived beyond public health statistics. Urine screening of life insurance applicants regularly showed that people could have sugar in their urine without diabetic symptoms, suggesting to some that the condition may have been more common than assumed. Reports of undiagnosed cases picked up in medical surveys of industry and the armed forces during the Second World War further fuelled these suspicions. One major survey of 1800 workers in the United States found twenty had diabetes with twelve of these only finding out through the survey.⁶³

In the two decades after the Second World War researchers in the Western world developed and debated new epidemiological techniques for studying non-communicable diseases. The multifactorial nature of chronic diseases made it difficult to distinguish causes from simple correlations. Chronic disease epidemiology employed a probabilistic epistemology, antithetical to the conclusiveness of established laboratory science.⁶⁴ Nevertheless, medical researchers, recognising the possibilities of environmental aetiological factors in these diseases, began developing new techniques such as large population-based surveys and prospective studies, which they believed could determine relative risk, incidence rates and the natural progression of latent, incipient or proto-disease states to frank disease.⁶⁵ By the mid-1960s, relative medical consensus around the explanatory framework of modern

⁶³ E.W. Gates, ‘Diagnosis of undetected diabetes: report of a study of a group of 1,800 individuals’, *Industrial Medicine*, 11, August 1942, pp.387–91.

⁶⁴ Rothstein, pp.50–51. Todd M. Olszewski, ‘The causal conundrum: the diet-heart debates and the management of uncertainty in American medicine’, *Journal of the History of Medicine and Allied Sciences*, 5 March 2014, doi: 10.1093/jhmas/jru001 (online advanced access). Berridge notes a distinctively British statistical tradition was important to the development of post-war chronic disease epidemiology in the UK: Virginia Berridge, *Marketing Health: Smoking and the Discourse of Public Health in Britain, 1945–2000*, Oxford, 2007, pp.32–34.

⁶⁵ Rodolfo Saracci, ‘Epidemiological Concepts Pre-1950 and their Relation to Work in the Second Half of the Century’, in Walter W. Holland, Jørn Olsen and Charles Du V. Florey, eds, *The Development of Modern Epidemiology: Personal Reports From Those Who Were There*, Oxford, 2007, pp.31–40; Virginia Berridge, ‘Post-war smoking policy in the UK and the redefinition of public health’, *Twentieth Century British History*, 14, 1, 2003, p.65.

epidemiology emerged with its institutionalisation as a discipline and formalised guidelines for causal inference.⁶⁶ The concept of ‘risk factors’ in chronic disease aetiology entered the common parlance of the medical profession.

Health officials applied these new epidemiological methodologies to diabetes before the more commonly cited modern epidemiological studies began.⁶⁷ The studies usually given historical and scientific significance focused on the major causes of death and ill health in Western countries: respiratory conditions, lung cancer and heart disease.⁶⁸ Early studies positing smoking as a cause of lung cancer by Richard Doll and Austin Bradford Hill in Britain and E.L. Wynder and E.A. Graham in the United States, both had their first reports appear in medical journals in 1950. For heart disease, scholars single out the Framingham Heart Study, also begun in 1950, as paradigmatic. This study followed a sample of healthy adults in a community in Massachusetts over a period of twenty years to determine risk factors for cardiovascular disease, eventually isolating diabetes as one of these in 1961. However, in 1946 the United States Public Health Service also began a survey of diabetes in Oxford, Massachusetts. This entailed screening a defined population over a significant length of time to chart the incidence and progression of the disease, factors associated with it, and potential strategies for intervention. Around 3500 of the town’s 5000 residents had their blood and urine screened. The overall prevalence of diabetes in the survey was 1.7 per cent, but the most significant findings were 30 ‘hidden diabetics’ and 25 who had blood sugar levels that sat between what was considered normal and diabetic. For every four known people with

⁶⁶ Luc Berlivet, ‘Association or Causation?’ The Debate on the Scientific Status of Risk Factor Epidemiology, 1947–c.1965’, in Virginia Berridge, ed., *Making Health Policy: Networks in Research and Policy after 1945*, Amsterdam, 2005, pp.39–74. The most influential of these guidelines were the 1965 ‘Hill’s causal criteria’ developed by Austin Bradford Hill, the British researcher who had helped establish smoking as a cause of lung cancer.

⁶⁷ Tattersall, pp.184–5; Mauck, pp.184–5.

⁶⁸ Saracci, pp.32–34; Rothstein, pp.238–9, 279–85.

diabetes at the time of the survey, the survey found another three previously undiagnosed cases.⁶⁹

The Oxford Massachusetts survey renewed the attention of the New Zealand medical community to diabetes statistics. In 1950, G.L. Brinkman of the Diabetic Clinic at Dunedin Hospital reported on the incidence and clinical appearance of diabetes in Dunedin city in the *NZMJ*. Using statistics from his clinic, the city's doctors and a breakdown of official mortality figures, Brinkman arrived at an incidence rate of 5.9 per 1000, which he then compared to similar international studies. He considered this rate to be an underestimation due to its exclusion of the undiagnosed – citing the Oxford, Massachusetts survey and the doctors who did not answer his questionnaires. Nevertheless, when Brinkman compared his incidence rate with other Western populations he found it was significantly higher. Dunedin's average mortality rate over 1945–49 of 3.7 per 10,000 was higher than Auckland, Wellington and eighteen cities from around the world; only New York was higher.⁷⁰ Brinkman thus deduced 'Dunedin must have one of the highest mortality rates due to diabetes mellitus in the world and as a corollary probably a higher than average incidence'.⁷¹ Finding little to explain the higher incidence in the clinical presentation of the disease, Brinkman tentatively attributed it to the more thorough investigation of the (comparatively small) community with doctors' providing regular urine testing. Although he only mentioned it in passing, Brinkman also claimed 'New Zealanders have the highest average calorific intake for any country', which

⁶⁹ Hugh Wilkerson and Leo Krall, 'Diabetes in a New England town', *Journal of the American Medical Association*, 135, 4, 1947, pp.209–16.

⁷⁰ G.L. Brinkman, 'A survey of diabetes mellitus in Dunedin city', *NZMJ*, 49, 273, October 1950, p.492. Brinkman compared the Dunedin rate with other international studies based on mortality figures which reported incidence rates of 3 to 4 per 1000 in England, 4 per 1000 in Massachusetts and 2.37 per 1000 in Germany. New York's higher prevalence was often explained by their high Jewish population.

⁷¹ Brinkman, p.493.

might also be a factor contributing to its diabetes rates.⁷² Brinkman concluded there was a need for comparable surveys of other areas in New Zealand.⁷³

Several Otago medical students responded to Brinkman's call for comparable surveys. One such survey in 1951 of urban Christchurch found an approximate incidence of diabetes of 5.06 per 1000 population. When compared to similar overseas studies, the authors argued 'From our survey and Brinkman's, the incidence of diabetes mellitus in New Zealand would appear to be markedly higher than that of England, United States of America or Germany.'⁷⁴ The students analysed Christchurch diabetes patient records and found 37.5 per cent of men and 63 per cent of women were overweight.⁷⁵ Although too small a sample for any definitive conclusions, the authors asserted this was in accordance with American life insurance statistics and large-scale patient studies conducted overseas that implicated the high association of obesity with the development of diabetes, particularly at middle age.⁷⁶ They argued that their findings warranted 'an anti-obesity campaign carried out with all modern means of advertising' and routine detection tests in hospitals and industry.⁷⁷

In 1959 the Health Department's Statistician, R. J. Rose, at the request of the new Director-General, Harold Turbott, made the Department's first estimate of diabetes prevalence in a specified community. Rose used Wellington's Island Bay parliamentary electorate as a geographical location as he could get relatively complete data from the eleven doctors and single public hospital. The analysis involved finding the number of known people with

⁷² *Ibid.*, p.498.

⁷³ *Ibid.*, p.500.

⁷⁴ 'Diabetes Mellitus in the Urban Area of Christchurch', Preventive Medicine Dissertation, University of Otago, 1951, p.9. See also 'Diabetes Mellitus in the Grey District', Preventive Medicine Dissertation, University of Otago, 1953.

⁷⁵ 'Diabetes Mellitus in the Urban Area of Christchurch', p.16.

⁷⁶ *Ibid.*, p.14.

⁷⁷ *Ibid.*, p.24.

diabetes and expressing them as the proportion of the population at risk in each age group. The survey found 188 cases clustered in the older age groups, a prevalence rate of 0.73 per cent.⁷⁸ While Turbott likely wanted the information to assess the extent of the diabetes problem as people aged, this was unachievable. As Rose pointed out,

The number of cases in the sample is much too small to accept the proportions in each age-group as reliable. In many cases the age [at onset] supplied was simply an approximation. Again we are dealing with the present age of cases under treatment and not the age at onset.⁷⁹

Like all previous New Zealand surveys, Rose could only comment on figures of already diagnosed people with diabetes and a small sample size.

By the middle of the twentieth century, statistical analyses of diabetes in New Zealand suggested the disease had been increasing for several decades. Limitations in this data initially led investigators and other observers to look to statistics and theories from similar countries to make sense of it. In any case, few considered the apparent increase to be a major problem: it was surely positive that people no longer so threatened by infectious diseases lived long enough to develop diabetes. Equally positive to contemporaries, was that rising rates of diabetes reflected the establishment of more medical facilities, improved diagnosis and therapy. Even those concerned that civilised lifestyles were to blame might not see this as negative considering that, at the tail end of the Depression, the Christchurch Hospital Medical Superintendent could claim the recent increase in diabetes was due to ‘improved standards of living’: ‘This disease is not one of depression, but probably of over-indulgence’.⁸⁰ Moreover, the extent of diabetes mortality and morbidity was not visible in statistics, which did not acknowledge diabetes contribution to much more significant causes of death like heart disease. While the statistics were sufficiently sketchy, the application of modern

⁷⁸ R.J. Rose to H.B. Turbott, 6 October 1959, ABQU 632 W4452 15/ 5/4/3 (0844), ANZW.

⁷⁹ Ibid.

⁸⁰ ‘Diabetes’, *Christchurch Times*, 27 April 1934.

epidemiological methods to diabetes in the 1960s would generate new understandings about the threat of diabetes to public health.

‘There has been a misconception ... that the Maori is comparatively free from these types of diseases’

In 1960 the Department of Health released the first report in a series of Special Reports, entitled *Maori-European Standards of Health*. The report’s author, R.J. Rose, analysed mortality and hospital admission figures from the 1950s to document the different illness experiences of Maori and European New Zealanders (Pakeha). Rose found that while it was generally well known that Maori had higher rates of infectious diseases than Pakeha the statistics indicated ‘that the Maori is affected to an even greater extent than the Pakeha in many diseases which occur in late middle life or old age’. According to Rose, this challenged the view that existed ‘even among physicians and health workers that the Maori is comparatively free from these types of diseases’.⁸¹ The report was the first to make statistical observations about diabetes in Maori.

The report painted a stark picture of Maori disease experience, including high mortality from diabetes, which Rose struggled to explain. He was not sure why apparently degenerative conditions had an early age of onset and were more likely to be fatal in Maori, but doubted Maori were constitutionally more susceptible to these diseases. He suggested some environmental factors, such as poor housing, might be responsible, as well as behavioural ones associated with ‘the traditional preference by many Maoris [sic] for the communal way of life’.⁸² For diabetes in particular, the Maori death rate for those aged between forty-five and sixty-four years old was four times greater than that of Pakeha, yet Rose believed diabetes

⁸¹ R.J. Rose, *Maori-European Standards of Health*, Department of Health Special Report No.1, Wellington, 1960, p.1.

⁸² *Ibid.*, p.2.

was unlikely to be more prevalent among Maori than Pakeha. He reasoned that ‘failure to seek medical advice and treatment would account for the much higher death toll at all ages among the Maori’.⁸³ Rose thought a cultural sense of stoicism made many Maori delay seeking early treatment.⁸⁴

While Rose’s report clearly documented the health inequalities between Maori and Pakeha, it could not accurately define the prevalence or incidence of diabetes. Historian Derek Dow has noted the report signaled a new statistical approach to Maori health research which was possible with the increased range and more accurate vital registration data available at this time.⁸⁵ Indeed, there were few statistics available to analyse Maori health in the early twentieth century. Demographer Ian Pool has noted that causes of death data for Maori were particularly inaccurate right into the 1940s.⁸⁶ It was only in 1945 that Maori deaths had to be medically certified; this allowed similar analysis of national trends to the earlier statistical studies of diabetes in Pakeha.⁸⁷ The Maori data, however, was still problematic because of the definition of ‘Maori’. Rose employed a biological definition, which was the most common (though not sole) legislative definition: that a Maori was an aboriginal person of New Zealand of at least half blood.⁸⁸ Contemporary social, medical and demographic researchers, however, were beginning to recognise tensions between biological and cultural constructions of racial identity due to the greater visibility of Maori within Pakeha society.⁸⁹ Even without the inherent difficulties with such categories, the report’s basis in hospital and mortality statistics

⁸³ Ibid., p.29.

⁸⁴ Ibid., p.4.

⁸⁵ Derek Dow, ‘Driving their Own Health Canoe: Maori and Health Research’, in Bronwyn Dalley and Margaret Tennant, eds, *Past Judgement: Social Policy in New Zealand History*, Dunedin, 2004, p.98; Ian Pool, *Te Iwi Maori: A New Zealand Population Past, Present and Projected*, Auckland, 1991, p.138.

⁸⁶ Pool, p.108.

⁸⁷ In his 1920 study of diabetes mortality, Hall noted that he had focused solely on the Pakeha population due to the unreliability of statistics on Maori and their separate compilation, however, noted ‘there were case records of various hospitals [which] supply definite evidence of Maoris [sic] suffering from the disease’: Hall, p.2.

⁸⁸ Rose, p.5; Pool, p.17.

⁸⁹ J.R. McCreary, ‘Population Growth and Urbanisation’, in Erik Schwimmer, ed., *The Maori People in the Nineteen-Sixties*, Auckland, 1968, pp.187–8.

meant it could not reveal how many ‘hidden diabetics’ lived in the community. The reported figures on diabetes in Maori may have still underplayed the extent diabetes was a problem for the population. Rose proposed field studies as a way to investigate ‘all aspects of sickness as it affects the Maori’ in rural, semi-rural and urban areas.⁹⁰

This recommendation recognised the increasing urbanisation of Maori in the mid-twentieth century. Pool has demonstrated that in the period 1945 to 1961 Maori had some of the highest rates of urbanisation, labour force transformation and population growth in the world.⁹¹ During World War Two, Maori went into the services and essential industries, and post-war employment opportunities, particularly in manufacturing, drew them increasingly from rural, tribal-based communities to New Zealand’s urban centres.⁹² By the 1960s, rural population figures ceased to increase, and the intra-urban migration of young families moving to new low cost and state housing developments in outer suburbs served to radically redistribute the proportion of Maori in the cities and the country.⁹³ In 1956, 65 per cent of Maori lived in rural areas and 35 per cent urban; in 1966 these figures had reversed to 38 per cent and 62 per cent respectively.⁹⁴ Over the same decade the Maori population would increase at around 4 per cent per annum, nearly double the rate of Pakeha.⁹⁵ These changes occurred alongside continued improvement in Pakeha living standards which exacerbated the relative inequalities between the two groups.⁹⁶ Contemporary observers worried about the social, economic and health problems Maori faced as they tried to adapt to modern, urban – Pakeha– lifestyles.⁹⁷

⁹⁰ Rose, p.4.

⁹¹ Pool, pp.147–51; 160.

⁹² M.P.K. Sorrenson, ‘Modern Maori: The Young Maori Party to Mana Motuhake’, in Keith Sinclair, ed., *The Oxford Illustrated History of New Zealand*, Auckland, 1993, pp.338–9.

⁹³ Pool, pp.153–9.

⁹⁴ *Ibid.*, p.154.

⁹⁵ *Ibid.*, p.141. This was on top of the migration gains and baby boom which the Pakeha community was experiencing.

⁹⁶ Sorrenson, pp.339–40.

⁹⁷ Erik Schwimmer, ed., *The Maori People in the Nineteen-Sixties*, Auckland, 1968. On the requirement of Maori to be both ‘modern’ and ‘traditional’ in the 1950s and 1960s, see Aroha Harris, ‘Maori and ‘the Maori

It was against this backdrop of increasing Maori urbanisation that in 1960 the Labour Prime Minister, Walter Nash, commissioned the head of the Department of Maori Affairs, J.K. Hunn, to report on the future direction of that Department. Released to the public a year later, the Hunn Report revealed Maori social and economic inequities and discriminatory or inappropriate government policies and practices in areas such as land, housing and education.⁹⁸ To address these issues, Hunn recommended a policy of ‘integration’ of Maori into Pakeha society with allowances for Maori to retain their cultural distinctiveness, and suggested speeding up Maori urbanisation to achieve this.⁹⁹ To critics, ‘integration’ was a euphemism for the continuance of assimilationist racial policies.¹⁰⁰ In the wake of the Report, the government did seek to eliminate some differences in health attributable to inequality or discrimination. The Health Department and other agencies identified the disparities in infant mortality rates as an area for action and also focused on tuberculosis in Maori, which remained a significant problem compared to the disease’s reduced importance in the Pakeha population.¹⁰¹

Entering the 1960s, Maori standards of health and the effects of integration with Pakeha society were topics of political, medical and epidemiological interest. Maori health appeared to be in a precarious position as it was threatened by both communicable and non-

Affairs’, in Bronwyn Daley and Margaret Tennant, eds, *Past Judgement: Social Policy in New Zealand History*, Dunedin, 2004, pp.191–206. For a critique of the post-war urbanisation story in national history, see Nepia Mahuika, ‘Revitalizing Te Ika-a-Maui: Maori migration and the nation’, *New Zealand Journal of History*, 43, 2, 2009, pp.133–49.

⁹⁸ The report was released by the new National government Minister for Maori Affairs, Ralph Hanan,

⁹⁹ Ministry for Culture and Heritage, ‘Jack Hunn’, updated 31 January 2014, URL: www.nzhistory.net.nz/people/jack-kent-hunn, accessed 14 September 2014.

¹⁰⁰ Sorrenson, p.343; Charlotte Williams, *More Power to Do the Work: Maori and the Health System in the Twentieth Century*, Wellington, 2007, p.23.

¹⁰¹ Derek D. Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Health*, Wellington, 1995, pp.196–200; Deborah Ann Dunsford, ‘Seeking the Prize of Eradication: a Social History of Tuberculosis in New Zealand from World War Two to the 1970s’, PhD thesis, University of Auckland, 2008, pp.99–149.

communicable disease. For the first time, statistics suggested diabetes was one of these threats.

‘To try and sort these things out further by actually using epidemiological methods’

In the early 1960s, cardiologist Dr Ian Prior responded to Rose’s call for population-based studies into the inequalities in health between Maori and Pakeha. Prior explained in his memoirs that, rather than using ‘methods like, “Hands up all of those who have got diabetes?”’, he wanted ‘to try and sort these things out further by actually using epidemiological methods’.¹⁰² Initially intending to document the true extent of Maori health problems, these studies soon presented Prior an opportunity to test a hypothesis that it was the increasing adoption of modern lifestyles – ‘Westernisation’ – which was ultimately behind cardiovascular and metabolic diseases such as diabetes.

While working as, a senior medical registrar and cardiologist at Wellington Hospital, Prior became the first director of the Wellington Medical Unit in 1969. The Unit, a branch faculty of Otago University Medical School, had a mandate to provide both patient care and a teaching and research programme in accordance with the director’s interests.¹⁰³ Prior had been researching atherosclerosis, anti-coagulants and cholesterol-lowering agents, but took the opportunity to develop a research programme for the Unit that addressed what he called a ‘blind spot’ of his specialty: epidemiology.¹⁰⁴ Inspired by ‘academic curiosity’ and his strong ‘sense of social justice’, Prior had no formal training in epidemiological methods and later admitted ‘effectively making up a theory of epidemiology as we went along’.¹⁰⁵ This was not

¹⁰² Ian Prior, *Elespie & Ian: Memoir of a Marriage*, Wellington, 2006, p.109.

¹⁰³ Dorothy Page, *Anatomy of a Medical School: A History of Medicine at the University of Otago, 1875–2000*, Otago, 2008, p.270.

¹⁰⁴ Ian Prior and Robert Beaglehole, ‘The Development of Epidemiology in New Zealand and the South Pacific’, in Holland, Olsen and Florey, p.310; Prior, *Elespie & Ian*, p.99.

¹⁰⁵ Prior and Beaglehole, p.310; Prior, *Elespie & Ian*, p.7.

unusual for the time; most epidemiologists before the late 1960s were physicians who came to the discipline through various clinical specialties.¹⁰⁶ Rose's request for population-based research on health inequalities appealed to Prior's personal and professional interests and the research mandate of the Unit enabled him to quickly and enthusiastically respond.

Prior held extensive discussions with Maori elders and communities before commencing his research. In his 2006 memoirs Prior recalled how he had consulted with John Rangihau, a student of his friend and lecturer in social work, John McCreary. McCreary and Rangihau had recently undertaken a social science study of a rural Maori community at Ruatahuna in the eastern North Island. Rangihau, who was a Maori Welfare Officer and young tribal leader in Ruatahuna, agreed to help Prior set up a health survey there if Prior could show it would benefit the people and agreed to do things his way.¹⁰⁷ Rangihau explained that Prior must meet with the community on their terms and get to know the people before mentioning the survey. Prior attended a tangi (funeral), a tribal meeting, and a Ringatū religious service and spent the night with many others in a whare (house) as a guest of Rangihau.¹⁰⁸ On reflection, Prior noted that this helped establish a relationship with the Ruatahuna people and provided a foundation lesson for all his subsequent epidemiological work – that the community and researchers needed to be understood as partners, not only in establishing the participants' health status, but in improving their health.¹⁰⁹

Prior also drew lessons from overseas studies, primarily the Tecumseh Community Health Survey. Early on he contacted Dr Fred Epstein of the University of Michigan for advice.

¹⁰⁶ Saracci, p.31.

¹⁰⁷ Prior, *Elespie & Ian*, p.104. For more on Rangihau, see Roka Rangihau, 'Rangihau, John Te Rangianiwaniwa 1919–1987', *Dictionary of New Zealand Biography*, updated 22 June 2007, URL: <http://www.dnz.govt.nz>, accessed 8 December 2014. For the previous study, see J.R. McCreary and J. Rangihau, *Parents and Children of Ruatahuna: A Report to the People*, Wellington, 1958.

¹⁰⁸ Prior, *Elespie & Ian*, pp.104–8. The mix of Maori or English terms in this sentence were what Prior used.

¹⁰⁹ *Ibid.*, p.108; Dow, 'Driving their Own Health Canoe', pp.100–2.

Epstein was responsible for directing the chronic disease part of the survey in Tecumseh which began in 1959. Tecumseh was a town about 30km north of Ann Arbor, Michigan with a population of 9,800 during the first survey round, 2,800 of whom lived in a rural environment. The Tecumseh study was among the first epidemiological studies of cardiovascular risk factors, but it also has special significance for the history of diabetes in helping develop a risk profile for the disease. Through successive prospective surveys of the same community the study connected disease processes in individuals to their wider social, cultural and environmental situation.¹¹⁰ The researchers believed such an approach could determine not only the common causes in community disease prevalence but that it could offer opportunities to develop preventive strategies, particularly targeting youth. This became one of Prior's major objectives.

The potential for epidemiological findings to feed into preventive policies also attracted the Health Department to support Prior's research. Prior later claimed to be inspired by Gisborne Medical Officer of Health, Harold Turbott's 1935 study of tuberculosis amongst the Maori. This study found the disease ten times more prevalent in Maori than in Pakeha populations and documented the inadequacies of housing and sanitation in the community.¹¹¹ Turbott, who became Director-General of Health in 1959, was very supportive of Prior's research and the Health Department was actively involved, primarily through having its nutritionist, Flora Davidson, on the survey team. This involvement continued into later studies both through financial support and in heart disease prevention initiatives.¹¹²

¹¹⁰ F.H. Epstein, T. Francis Jr., N.S. Hayner, B.C. Johnson, M.O. Kjelsberg, J.A. Napier, L.D. Ostrander Jr., M.W. Payne and H.J. Dodge, 'Prevalence of chronic diseases and selected physiologic variables in a total community, Tecumseh, Michigan', *American Journal of Epidemiology*, 81, 3, 1965, p.307.

¹¹¹ Prior and Beaglehole, p.307.

¹¹² *Ibid.*, pp.310–11.

In January 1962 Prior and his survey team began collecting their data. The team included a physician, paediatrician, neurologist, nutritionist, four technical assistants and three Maori members responsible for taking a census of the district, transport liaison and translation. The aim was to get data on the health status of an entire Maori population — a cross-sectional ‘chunk population survey’ — for which they achieved a remarkable 99 per cent participation rate of those who were in the area at the time. The survey involved more than just medical investigation; it tested for a range of disease and disease-predisposing conditions, and measured dietary intakes, anthropometric data and assessed social and economic conditions. For those aged over fifteen years old, the focus was on finding the prevalence, connections between, and predisposing factors to cardiovascular and metabolic disorders, including diabetes.¹¹³ The researchers also referred survey participants to their general practitioners and provided ongoing health care and support through the Wellington Medical Unit.

The survey found a very high prevalence of diabetes in the community. Participants had their urine tested and those with abnormally high sugar present (glycosuria) then underwent a glucose tolerance test. For this test the team took measurements from fasting and two hours after participants had consumed 50–100g of glucose; they found eleven people with levels indicating diabetes. Two more had gross glycosuria and one who had a negative urine test was admitted to hospital days later with elevated blood sugar. These cases, combined with four previously known cases, equated to eighteen people with diabetes and a community prevalence rate of 11 per cent in females and 6 per cent in males. Prior was concerned that these rates were an underestimate, because the urine tests had been conducted with no regard to when the participants had last eaten or drunk; had they tested after a meal they would have

¹¹³ Ian Prior, ‘A health survey in a rural Maori community, with particular emphasis on the cardiovascular, nutritional and metabolic findings’, *NZMJ*, 61, 359, July 1962, p.344; I.A.M. Prior, B.S. Rose and F. Davidson, ‘Metabolic maladies in New Zealand Maoris [sic]’, *British Medical Journal*, 1, 5390, 1964, p.1069.

found more.¹¹⁴ Of the eighteen people with diabetes, the researchers' considered thirteen were significantly overweight.

The Ruatahuna survey was an important milestone in establishing the significance of obesity-related diabetes in Maori. As Prior explained, 'The high prevalence of diabetes in both sexes has not been previously described in the Maori but it is not surprising in view of the significant metabolic abnormalities that are associated with obesity'.¹¹⁵ The group had high levels of obesity; for women aged between thirty and forty-nine years old, 50 per cent exceeded 120 per cent normal weight (using the Actuary Society of America tables which were the common standard at the time). Prior suggested excess calories and inactivity were probably responsible for the high level of obesity and diabetes. This was particularly so for the women who tended to eat similar quantities of food as their husbands who engaged in hard physical labour. The diets were relatively simple and monotonous, based on bread, potatoes, sugar and butter. The people ate traditional vegetables such as puha and it was customary for a heavy evening meal of meat. Prior made no aetiological conclusions, however, about any particular dietary factor.¹¹⁶

The findings at Ruatahuna appeared to challenge Prior's hypothesis that an isolated community of Maori would be less prone to 'Western' diseases like diabetes. Did this mean Maori had a genetic predisposition to diabetes? Prior intimated that the relatively high degree of intermarriage in the group (in contrast to the Maori population as a whole, the Ruatahuna people had minimal Pakeha blood) may have emphasised their heredity susceptibility. Almost all of those with an abnormal result had someone who suffered from diabetes in their

¹¹⁴ Prior, 'A Health Survey', p.344. See Chapter Three for a discussion of the uncertainties around diagnostic criteria and methods in diabetes surveys, and their implications.

¹¹⁵ *Ibid.*, p.347.

¹¹⁶ *Ibid.*, pp.346–7.

whakapapa (genealogies).¹¹⁷ Prior was wary of making firm aetiological conclusions based on a single survey, and planned a prospective study to assess the development and incidence rate of disease in this group compared to a less 'isolated' rural Maori group and an urban Maori group. Prior hypothesised that in larger Maori communities the genetic influence would be reduced, 'while adoption of a more Western way of life by the urban groups may reveal interesting trends' – most likely more obesity and more diabetes.¹¹⁸

Following the Ruatahuna survey, Prior's team made studies of two other Maori communities. The first was a less isolated rural group in Tikitiki on the East Coast of the North Island. Again they achieved an impressive participation rate of 96 per cent of the whole community. The second group, from the central North Island town of Rotorua, had lived in urban conditions for at least ten years. The researchers randomly selected this group from a household census; 95 per cent of those asked participated in the survey. Using the same diabetes detection methods, the survey team found the Tikitiki group had prevalence rates of 10 per cent in men and 7 per cent in women; for the Rotorua group these rates were 9.8 per cent in men and 4 per cent in women.¹¹⁹ Prior had planned on comparing the three groups to work out the relative influence of suspected predisposing factors in diabetes. The survey found, however, no significant differences between the urban and rural Maori groups in disease prevalence or dietary intake, which was universally high in calories, fat and sugar. The researchers thus suggested that the environmental changes in terms of diet and obesity levels had been longstanding enough to create the similar disease rates.¹²⁰

¹¹⁷ I.A.M. Prior and F. Davidson, 'The epidemiology of diabetes in Polynesians and Europeans in New Zealand and the Pacific', *NZMJ*, 65, 375, June 1966, p.381.

¹¹⁸ Prior, 'Metabolic maladies', p.1069.

¹¹⁹ Prior and Davidson, pp.376–7. This rate is for all adults over twenty years old. The Ruatahuna rate for over twenty-year olds was 8 per cent in men and 13 per cent in women.

¹²⁰ I.A.M. Prior, B.S. Rose, H.P.B. Harvey and F. Davidson, 'Hyperuricaemia, gout, and diabetic abnormality in Polynesian people', *The Lancet*, 287, 7433, 12 February 1966, p.337.

The collated results painted a depressing picture of Maori morbidity. Across all three groups there were high levels of obesity, 50 per cent had hyperuricaemia (elevated levels of uric acid in the blood), manifest ischaemic heart disease and hypertension in many women, gout in 10 per cent of men, diabetes in 9.2 per cent of men and 7 per cent of women, and 29 per cent of those with diabetes also had gout.¹²¹ There was a statistically significant correlation between number of pregnancies and the likelihood of women developing diabetes; 90 per cent of the females with diabetes over the age of 40 had had five or more pregnancies.¹²² This evidence provided more questions than it resolved: was being a New Zealand Maori a risk factor for diabetes and associated pathologies, or, could environmental influences explain their high prevalence?¹²³ The major funder of medical research in New Zealand, the Medical Research Council (MRC), considered the extent and nature of the problems warranted ‘further studies in Polynesians outside of New Zealand’.¹²⁴

In 1964 the Wellington Hospital Medical Unit undertook health surveys of two groups of Cook Island Maori to further test the Westernisation hypothesis. Historian Deborah Dunsford and colleagues have explained that, at this time, it was common for health problems identified in Maori to act ‘as a sentinel for other Pacific populations’ as there was ‘a strong focus on the category “Polynesian” as a meaningful biological entity’.¹²⁵ The Unit also saw the Cook Islands as an ideal testing ground for the Westernisation hypothesis because of its distinct

¹²¹ *Appendices to the Journal of the House of Representatives* (AJHR), H.31b, 1968, p.17.

¹²² Prior and Davidson, p.381. While this was put down to weight gain with successive pregnancies, it may also have been a sign of unrecognised gestational diabetes, only established firmly as a separate condition in 1964, and suspected to bring on diabetes in the mother in later life.

¹²³ Prior questioned whether the evidence ‘suggested that the Maori in New Zealand would remain at high risk irrespective of long-term material improvement in their environment’: I.A.M. Prior, H.P.B. Harvey, M.N. Neave and F. Davidson, *The Health of Two Groups of Cook Island Maoris* [sic], Department of Health Special Report No.26, Wellington, 1966, p.1.

¹²⁴ AJHR, H.31b, 1968, p.17.

¹²⁵ Deborah Dunsford, Julie Park, Judith Littleton, Ward Friessen, Phyllis Herda, Pat Neuwelt, Jennifer Hand, Philippa Blackmore, Sagaa Malua, Jessica Grant, Robin Kearns, Linda Bryder and Yvonne Underhill-Sem, *Better Lives: The Struggle for Health of Transnational Pacific Peoples in New Zealand, 1950–2000*, Auckland, 2011, pp.21–2.

groups living under varying degrees of economic development and exposure to European culture and diets.¹²⁶ Both the MRC and the World Health Organization (WHO) were, according to Prior, ‘intrigued with the data from the early studies in New Zealand’ and provided funding for the studies.¹²⁷ As with the Rotorua sample, the research team randomly chose a group of people from the main town in the Cook Islands, Avarua (Rarotonga) who had lived under urban conditions for more than ten years. The participation rate was 98 per cent. The other group from the small coral atoll of Pukapuka consisted of the entire adult population.¹²⁸ This group was one of the most isolated Pacific populations and had experienced very little social change since New Zealand ethnographers Ernest and Pearl Beaglehole studied the population in 1935. They had also been previously subject to a MRC survey in 1951 providing some background to the health status of the population for comparative analysis.¹²⁹

The results of the Cook Island surveys again highlighted the importance of obesity in accounting for differing diabetes prevalence rates. Essentially the same survey and testing methods were employed as with the New Zealand Maori groups, except that a glucose tolerance test was also administered to all those aged between sixty and sixty-nine years old. These additional tests showed the close relationship between glucose intolerance and obesity in older Rarotongan women but they also altered the total survey prevalence rates upwards.¹³⁰ The researchers calculated diabetes prevalence in the Cook Island samples at 4.5 per cent for Rarotongan men, 1.6 per cent for Pukapukan men, 6.6 per cent for Rarotongan women, and

¹²⁶ Prior, Harvey, Neave and Davidson, p.1.

¹²⁷ Prior and Beaglehole, p.309.

¹²⁸ Prior and Davidson, p.376.

¹²⁹ Prior, Harvey, Neave and Davidson, p.1.

¹³⁰ *ibid*, p.24. Researchers at this time were becoming aware that older women in particular had a higher renal threshold, which meant they might have diabetes despite an absence of glycosuria. Alternatively, other researchers believed that glucose tolerance diminished with age in all people and was not necessarily pathological, in other words, they argued diagnostic blood sugar levels for diabetes should be age specific. See Chapter Three.

3.1 per cent Pukapukan women.¹³¹ They attributed the noticeable difference in prevalence between the urban and traditional groups to obesity, which was almost universal in the Rarotongan people with diabetes. The general conclusions from the study were that both groups carried the genetic factors for diabetes, but obesity in the Rarotongan group made them more likely to develop the disease.¹³²

Following its Maori and Cook Island studies, the Wellington Unit made a population survey of a typical Pakeha community. Prior and his team chose the borough of Carterton, just north of Wellington, as they believed it was ‘representative of a New Zealand country town with a stable population’.¹³³ Conducted in late 1964, the Carterton survey was the first of its kind for a Pakeha community and, at the time, the most extensive in Australasia. Media reports emphasised that the survey would ‘allow the first comparison to be made with findings in similar groups of people living in other Western-type countries’.¹³⁴ The research team randomly selected a sample of adults over twenty years of age from a household census for the survey and achieved a 90.8 per cent participation rate.¹³⁵ The survey found twelve people with diabetes but only two who had been previously undiagnosed. The diabetes prevalence rates were significantly lower than in the Maori groups: 1.5 per cent in men and 3.9 per cent in women. Likewise obesity was less common; 16 per cent in Pakeha women compared to 45 per cent in Maori women and 8 per cent in Pakeha men compared to 22 per cent in Maori men.¹³⁶ The low figures ran close to the Pukapukan sample of Cook Island Maori. In a 1966

¹³¹ Prior and Davidson, p.377.

¹³² Prior, Harvey, Neave and Davidson, p.40.

¹³³ I.A.M. Prior, J.G. Evans, R.B. Morrison and F. Davidson, ‘The Carterton study 1. Sampling methods and response rates’, NZMJ, 68, 436, September 1968, p.150.

¹³⁴ Newspaper cutting, n.d., Surveys and Special Topics – Public Health Survey – Carterton, 1965, ABQU 632 W4452 27/ 13/38 (0782) ANZW.

¹³⁵ Prior, Evans, Morrison and Davidson, p.150.

¹³⁶ ‘Carterton Medical Survey: Report of the 1965 Medical Survey’ ABQU 632 W4452 27/ 13/38 (0782) ANZW.

NZMJ article analysing all of their surveys, Prior and Davidson concluded that obesity was ‘the important factor contributing to the different prevalence rates’ of diabetes.¹³⁷

This article was a response to the WHO’s recent request for comparative epidemiological studies of diabetes. In November 1964 a WHO Expert Committee on Diabetes Mellitus met to discuss and review current knowledge on the disease, which it suspected was becoming a global public health problem. The Committee’s subsequent report noted ‘indications of a rapid increase in the disease that are in complete accord with the recognized clinical associations between diabetes and increased food consumption, reduced physical exertion and obesity’.¹³⁸ The Committee emphasised a need for ‘suitable epidemiological information about glucose tolerance in various populations of various races and cultures in different countries’ and called for surveys to both find undiagnosed cases and to examine the natural history of diabetes and its aetiological factors.¹³⁹ In Prior and Davidson’s comparative NZMJ article they stated that up to 80 per cent of people with diabetes in the Maori and Pacific groups were only discovered during the surveys.¹⁴⁰ In contrast, 83 per cent of the Carterton people with diabetes already knew they had the condition. This implied that affluent Westerners had more opportunity to access diagnoses than indigenous and developing populations, justifying the WHO’s concerns of a hidden problem.

In line with WHO’s recommendation, the Wellington Unit’s prospective studies helped elucidate more about the natural history of diabetes. Over 1968 to 1969 and again in 1974 the Wellington Unit reexamined the people of Ruatahuna, Tikitiki and Rotorua. To meet updated WHO standards these examinations used blood rather than urine screening; participants gave

¹³⁷ Prior and Davidson, p.383.

¹³⁸ WHO, *Diabetes Mellitus: Report of an Expert Committee*, Technical Report Series No.310, Geneva, 1965, p.6.

¹³⁹ *Ibid.*, pp.12, 37.

¹⁴⁰ Prior and Davidson, p.382.

blood plasma samples one hour after a 100g glucose load following an overnight fast.¹⁴¹ The final round of tests revealed an age-standardised prevalence of diabetes, in both men and women, of 9.6 per cent. Although considerable migration had occurred from the original study areas, the research team re-examined 92 per cent of those still alive and obtained data on those who had died, drawing on information from doctors, hospital records and death certificates.¹⁴² This longitudinal study showed that diabetes increased the risk of death in Maori from not just coronary heart disease but all causes, a trend particularly marked in the men.¹⁴³

These longitudinal studies of diabetes in Maori also contributed to the ongoing debate about whether a ‘thrifty gene’ was responsible for diabetes. In 1962 James V. Neel, at the University of Michigan Medical School in Ann Arbor, proposed that the genes which predisposed some people to diabetes could have been historically advantageous, enabling them to store fat during periods of food abundance as reserves for times of famine. When humans were hunter-gatherers exposed to uncertain food supplies and regular exercise, the thrifty gene served them well. In modern life, sedentariness and the ability to indulge a ‘hypertrophied appetite’ meant the thrifty genotype was ‘rendered detrimental by “progress”’.¹⁴⁴ Neel offered this as a working hypothesis to explain the high prevalence of diabetes in the affluent Western world.

Over the 1960s and 1970s as reports came in, including those of the Wellington Unit, of even higher rates of diabetes in indigenous populations, many began to consider an ethnic

¹⁴¹ For the new diagnostic standards, see Chapter Three.

¹⁴² I.A.M. Prior, R. Beaglehole, Flora Davidson and Clare E. Salmond, ‘The relationships of diabetes, blood lipids, and uric acid levels in Polynesians’, *Advances in Metabolic Disorders*, 9, 1978, p.246.

¹⁴³ *Ibid.*, p.248.

¹⁴⁴ James V. Neel, ‘Diabetes mellitus: a “thrifty” genotype rendered detrimental by “progress”?’’, *American Journal of Human Genetics*, 14, 1962, pp.353–62.

predisposition to diabetes based on the ‘thrifty gene’. Prior and colleagues believed that the thrifty gene hypothesis was ‘an attractive one’ to explain diabetes in the Pacific, because the dangers of sea-faring migration of Pacific peoples likely conferred obesity with a survival value. Yet they also argued that the similar rates of obesity and diabetes in Pukapukans and Pakeha compared to the much higher rates in Maori signaled ‘that the Polynesian may not have any particular predisposition in the absence of obesity’.¹⁴⁵ This was also the key conclusion of American diabetes epidemiologist Kelly West in his extensive studies of diabetes in ‘new world’ populations which were reported in the 1970s.¹⁴⁶

Neel revisited his hypothesis in 1982. If a predisposition to diabetes had an evolutionary basis it would mean diabetes would be long-standing in these populations, but Neel found little evidence to indicate this. He thus argued that the adaptations from a hunter-gatherer existence which Europeans made over several centuries were being ‘telescoped’ in these populations now undergoing more rapid modernisation and culture change.¹⁴⁷ Neel cited Prior’s findings on diabetes in Polynesian groups as evidence that diabetes in these populations was a modern situation most likely brought about by changes in diet contributing to obesity. Over the 1980s and 1990s the thrifty genotype remained a popular, although unproven, explanation of obesity itself. It was also used to explain a non-white predisposition to the ‘metabolic syndrome’ of a constellation of diabetes and cardiovascular disease risk factors which studies like Prior’s had begun to demonstrate.¹⁴⁸

¹⁴⁵ Prior, Beaglehole, Davidson and Salmond, pp.242–4; I.A.M. Prior, ‘Nutritional problems in Pacific Islanders: The 1976 Muriel Bell memorial lecture’, *Proceedings of the Nutrition Society of New Zealand*, 1, 1976, p.23.

¹⁴⁶ K.M. West, ‘Diabetes in American Indians and other native populations of the new world’, *Diabetes*, 23, 10, 1974, pp.841–55; Kelly M. West, *Epidemiology of Diabetes and Its Vascular Lesions*, New York, 1978.

¹⁴⁷ J.V. Neel, ‘The thrifty genotype revisited’, in J. Köbberling and R. Tattersall, eds, *The Genetics of Diabetes Mellitus: Proceedings of the Sero Symposium, Volume 47*, London, 1982, pp.283–4.

¹⁴⁸ Prior and Neel’s engagement with each other’s research was most likely the result of Neel and colleague Dr R. Ward’s involvement in developing a protocol for tracing the genetic homogeneity of Tokelau Islanders in the Tokelau Island Migrant Study: *AJHR*, 1973, E11, p.35; Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, pp. 389–93, 406. Neel believed refined carbohydrate and sugar was the dietary factor directly responsible for increased diabetes, however this remains a controversial point: see J.V.

The Wellington Unit's studies were among the first to find 'epidemics' of diabetes in the Pacific.¹⁴⁹ As a response to concerns about ethnic inequalities in health status, they began to show how lack of access to health services might impact on different morbidity and mortality patterns for diabetes in Maori and Pacific populations. However, the studies' key contribution to contemporary understandings of diabetes was their confirmation that a broad spectrum of diabetes prevalence in 'Polynesian' peoples correlated to levels of obesity. This suggested the primacy of environmental or lifestyle influences in the disease's development and thus potential for preventive intervention.

An 'experiment of nature': the Tokelau Island Migrant Study (TIMS)

In the late 1960s Prior found an 'experiment of nature' – the migration of Tokelau Islanders to New Zealand – which he believed offered a unique opportunity to confirm the hypothesis that the degree of Westernisation in Polynesian populations could be correlated with the extent of their chronic health problems, like diabetes.¹⁵⁰

In the second half of the twentieth century New Zealand experienced an influx of migrants from the Pacific Islands. Rapid population growth and agricultural decline on many Pacific Islands led to pressures on land and food resources and encouraged migration. During and after the Second World War, migrants came to plug unskilled and semi-skilled labour force gaps in New Zealand. This migration increased rapidly in the prosperous 1960s on the back of

Neel, 'The "thrifty genotype" in 1998', *Nutrition Review*, 57, 5 Pt 2, May 1999, pp.2–9. Alternative theories on the mechanisms behind genetic predisposition to Type 2 diabetes are still a subject of debate among genetic and epidemiological researchers and many variations on the thrifty gene hypothesis continue to appear.

¹⁴⁹ West, *Epidemiology of Diabetes*, p.204; Norman R. Sloan, 'Ethnic distribution of diabetes mellitus in Hawaii', *Journal of the American Medical Association*, 183, 6, February 1963, pp.419–24.

¹⁵⁰ Prior, 'Polynesian Health', p.113.

full employment and industrial development.¹⁵¹ The proportion of Pacific Islanders living permanently in New Zealand rose from 0.01 per cent in 1945 to 1 per cent in 1966.¹⁵² Permanent migration figures, however, underplay the ‘transnational lives’ of Pacific people, the importance of which Dunsford and colleagues have recently highlighted.¹⁵³ Many Pacific people came to New Zealand for short spells. Migrants generally moved from rural villages or outer islands to local port towns and then on to the urban areas of New Zealand, particularly Auckland, where they could find jobs and housing. Young people arrived first followed by extended family members – what sociologists call chain migration – while links were frequently maintained with kin in their homeland villages.¹⁵⁴

In the 1960s there was an acceleration of migration to New Zealand from the Tokelau Islands. The Tokelau Islands consisted of three tiny atolls under the governance of New Zealand since 1948. Throughout the 1950s the New Zealand government had mostly left the atoll dwellers to their own devices and they retained their own social and cultural values and institutions within a subsistence economy. By the 1960s, however, New Zealand government officials began worrying about the future prospects of those in Tokelau as its 1,080 hectares of landmass was in danger of becoming severely overcrowded.¹⁵⁵ In 1963 the New Zealand Department of Labour began assisted migration and resettlement programmes for young single Tokelauan men and women and scholarship schemes for children to study in New Zealand. In January 1966 a severe cyclone hit Tokelau, causing extensive damage to the atolls, and providing impetus for an expanded official resettlement programme from mid-

¹⁵¹ Mary Boyd, ‘New Zealand and the Pacific’, in Keith Sinclair, ed., *The Oxford Illustrated History of New Zealand*, Auckland, 1993, p.314.

¹⁵² J.R. McCreary, ‘Population Trends in the Pacific’, in WHO, *Cardiovascular Epidemiology in the Pacific: WHO Meeting of Investigation in Wellington, New Zealand, 9–14 February 1970: Report*, Wellington, 1970, p.6.

¹⁵³ Dunsford et al, pp.5–19.

¹⁵⁴ McCreary, p.6; Boyd, p.315.

¹⁵⁵ A. Hooper and J. Huntsman, ‘Tokelau, New Zealand, and the United Nations: 1948 to 1984’, in Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, pp.78–80.

1966. The programme brought 152 people to New Zealand in its first two years, but chain migration brought many more.¹⁵⁶ By the mid-1970s there were more Tokelauans in New Zealand than in Tokelau.¹⁵⁷

Prior saw the Tokelauan migration to New Zealand as an opportunity to confirm his deductions about the influence of a changing environment on chronic disease patterns. He proposed a survey of Tokelauans before migration from their traditional societies then at regular intervals after their migration to their new, modern homes in New Zealand's urban centres. Such an epidemiological study would be the first to compare the health status of migrants against non-migrants from the same population.¹⁵⁸ Prior obtained MRC funding and began medical examinations to gather the baseline data of almost the entire population of the atoll of Fakaofu in 1968. While originally designed to investigate Prior's main interest at this time, the risk factor of blood pressure in cardiovascular disease, the study quickly became a more complex analysis of chronic diseases and their risk factors; the MRC's 1967 annual report noted 'Of particular interest will be the effect of the environmental change on the incidence of diabetes'.¹⁵⁹ Logistical and scheduling issues meant the baseline data for the other two atolls could not be collected until 1971.¹⁶⁰

Prior's expanding interest into epidemiology did not go unnoticed. In the late 1960s, the time and energy Prior was devoting to epidemiological work was beginning to create tensions with some of his colleagues. One, in particular, mocked some of Prior's methodologies: "What is it

¹⁵⁶ Ibid., pp.80–82.

¹⁵⁷ Albert F. Wessen, 'Ian Prior and the Tokelau Island Migrant Studies', in Prior, Howden-Chapman and Woodward, p.17.

¹⁵⁸ Ibid., p.19.

¹⁵⁹ AJHR, H31b, 1968, p.18; Albert E. Wessen, 'The Tokelau Island Migrant Study: an introduction', in Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, pp.9–10.

¹⁶⁰ Wessen, 'The Tokelau Island Migrant Study: an introduction', p.17.

anyway, but pinching Maoris' [sic] bottoms?"¹⁶¹ Prior's friend and Professor of Medicine at Otago Medical School, John Hunter, also worried that Prior's fieldwork outside Wellington was becoming detrimental to his clinical responsibilities and they needed to rethink the organisation of the Medical Unit.¹⁶² In early 1969 both the Wellington Hospital Board and University of Otago considered reconstituting the Wellington Medical Unit into a specialist epidemiology research unit and requested Prior begin drafting its terms of reference, staffing and research plans.¹⁶³

At the same time as these discussions on the Unit's reorganisation, Prior was arranging a special WHO Working Group Meeting on Research Methodology of Cardiovascular Disease Studies in the Pacific. In July 1969 the WHO proposed to designate the Medical Unit as a Collaborating Institute for Studies on Cardiovascular Epidemiology, which meant financial support for its research and important connections with experienced epidemiologists.¹⁶⁴ Prior consulted with Dr Ken Newell, Director of the WHO's newly formed Division of Research in Epidemiology and Communications Science, and Dr Z. Fejfar, Director of the WHO Cardiovascular Diseases Unit, to plan the meeting.¹⁶⁵ Held at Wellington's Victoria University over 9–14 February 1970, the event gave international relevance and respectability to the new Epidemiology Unit's work. Overall the discussions at the meeting emphasised interdisciplinary planning between epidemiologists and social scientists in Pacific studies. As such, the Tokelau Island Migrant Study (TIMS) would now have a more formal relationship with Auckland University anthropologists Dr Anthony Hooper and Judith Huntsman, who

¹⁶¹ Prior, *Elespie & Ian*, p.110. The quoted comment referred to the use of callipers to take skin fold measurements to estimate the percentage of body fat of participants.

¹⁶² *Ibid.*, p.112.

¹⁶³ Medical: Epidemiological Unit, 1969–77, ABRR 7273 W4744 27 96/27/1, ANZW.

¹⁶⁴ J. Karefa-Smart to Ian Prior, 17 July 1969, ABRR 7273 W4744 27 96/27/1, ANZW. The WHO was gradually building up a network of collaborating centres to investigate specific problems to assist in the prevention and control of cardiovascular diseases: see WHO, *Cardiovascular Epidemiology in the Pacific*, p.3.

¹⁶⁵ Ian Prior to Dr Z Fejfar and Dr K Newell, n.d., [this was a copy Prior forwarded D.P. Kennedy, 7 February 1969], ABRR 7273 W4744 27 96/27/1, ANZW. On Newell, see Prior, *Elespie & Ian*, pp.112–13.

were conducting an ethnographic study of Tokelau Islanders at the time, and come under the guidance of medical sociologist and head of the WHO Behavioural Science Unit, Professor Albert Wessen.¹⁶⁶

The Working Group meeting and the separate visit of renowned British epidemiologist Professor Archie Cochrane brought Prior's research under closer scrutiny.¹⁶⁷ Cochrane, Director of the British Medical Research Council's Epidemiological Research Unit at Cardiff, had concerns about Prior's enthusiasm for beginning new work before completing the task at hand, the lack of a senior colleague to offer critique, the lack of statistical help available, and the free availability of funding without demands for justification.¹⁶⁸ Meanwhile, the WHO representatives 'were especially anxious to establish machinery for adequate supervision' of TIMS now the WHO was part-funding it. Cochrane met with Prior to help him establish a research protocol, then returned to the New Zealand MRC with his recommendation that as Prior's 'main skill lies in the field work ... he should concentrate on this and not necessarily insist on retaining his own hospital clinical attachment'.¹⁶⁹ The Hospital Board subsequently agreed to this recommendation, and the Unit solely focused on epidemiology from May 1970.¹⁷⁰ The MRC also agreed to Cochrane's recommendation that it finance the salaries of a statistician and senior epidemiologist, and the WHO's recommendation to establish a TIMS Sub-Committee of the MRC's South Pacific Research Committee to oversee the study.

¹⁶⁶ For the fullest account of the ethnographic study see the chapters contributed by Hooper and Huntsman in Wessen, ed., *Migration and Health in a Small Society*, pp.21–240.

¹⁶⁷ 'Submission from Scientific Secretary [J.V. Hodge]', March 1970, Dr Prior's Research in Epidemiology', Programme Grants – Prior – Epidemiology Research Unit, 1969–73, YCBN 5815 170b, Archives New Zealand, Auckland (ANZA).

¹⁶⁸ 'Discussion with Profs Dick Lovell and Archie Cochrane on Ian Prior's epidemiological work', 12 February 1970, YCBN 5815 170b, ANZA.

¹⁶⁹ 'Submission from Scientific Secretary'.

¹⁷⁰ C.L. Tucker to Ian Prior, 3 April 1970, ABRR 7273 W4744 27 96/27/1, ANZW. A.F. Wilton to Ian Prior, 11 May 1970; Ian Prior, 'Report to Wellington Hospital Advisory Committee regarding Clinical Epidemiology Unit', 6 May 1970, ABRR 7273 W4744 27 96/27/1, ANZW.

Victoria University's John McCreary served as Chair of the Sub-Committee, Prior as Director of Epidemiological Studies and Hooper as Director of Behavioural Studies.¹⁷¹

TIMS now had an expanded study protocol. All adults over fifteen years of age in both Tokelau and New Zealand participated in standardised sociological interviews (which the anthropologists administered) and medical examinations (by Prior and his team).¹⁷² The researchers collected data on physiological and behavioural risk factors for a range of chronic diseases in three survey rounds: in the Tokelau Islands these were in 1968–71, 1976, and 1982; in New Zealand they were in 1972–74, 1975–77 and 1980–81. Prior's team used the same screening method for diabetes as in the 1968–69 and 1974 surveys of Maori population groups, which allowed for direct comparisons.¹⁷³ For more than a decade the study tracked almost the whole Tokelauan population; approximately 99 per cent in round one, 92 per cent in round two and 80 per cent in round three.¹⁷⁴

The final analysis of the 1968–82 study found that the urbanisation and migration of Tokelauans had a significant influence on the development of diabetes.¹⁷⁵ The researchers analysed the changing prevalence of diabetes over the three survey rounds in a sample of all the residents of Tokelau, and all the Tokelauan migrants to New Zealand, aged between

¹⁷¹ AJHR, H31b, 1971, p.8. Other members were Dr G. Blake-Palmer, representing the Health Department, Mr J. Springford representing the Department of Maori and Island Affairs, Mr J.A.R. Miles representing the South Pacific Research Committee, Hodge for the MRC and Cochrane and Wessen as corresponding members.

¹⁷² Children were also included in the study but were subject to different medical examinations. For a full account of all aspects studied and the methods used, see Appendix B in Albert E. Wessen, ed., *Migration and Health in a Small Society*, pp.399–413.

¹⁷³ Over the course of the study, new international standards for blood glucose testing were established. However, in the interests of obtaining comparable longitudinal data the researchers did not change their screening methods in the later survey rounds.

¹⁷⁴ Albert F. Wessen, 'Ian Prior and the Tokelau Island Migrant Studies', p.18.

¹⁷⁵ I.A.M. Prior, 'Migration and Chronic Disease', in Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, p.363. See also T. Østbye, T.J. Welby, I.A.M. Prior, C.E. Salmond and Y.M. Stokes, 'Type 2 (non-insulin dependent) diabetes mellitus, migration and westernisation: The Tokelau Island Migrant Study', *Diabetologia*, 32, 1989, pp.585–90.

thirty-five and seventy-four years old, for whom complete data were available.¹⁷⁶ At each survey round, the prevalence of diabetes was higher among migrants than among the non-migrants, but both groups showed a trend towards more diabetes with each successive round.¹⁷⁷ The age-standardised prevalence in male migrants rose from 7.5 per cent to 11 per cent compared to a rise from 3 per cent to 8.7 per cent in non-migrant males; in females the rates went from 10.8 per cent to 19.9 per cent and 7 per cent to 14.3 per cent respectively. Migrants also had a lower age of onset of diabetes.¹⁷⁸

The differences between migrants and non-migrants were not as stark as the research team expected. The study was premised on an expectation that non-migrants would remain in a subsistence economy and experience little change to their lifestyles, while migrants to New Zealand would face an abrupt transition into a wage economy where they would have to adapt to a new climate, diet, and work and leisure patterns without their traditional support structures. This premise underlying the ‘natural experiment’ did not eventuate quite as planned. The Tokelauans travelled frequently between the atolls and New Zealand with only 35 per cent remaining in their supposed home (whether Tokelau or New Zealand) between survey rounds one and three.¹⁷⁹ Moreover, Hooper and Huntsman’s anthropological study found that migrants to New Zealand tended to seek social support and friendship by re-establishing tight-knit Tokelauan communities in New Zealand. The research team believed this community cohesiveness had a protective factor against some conditions such as high blood pressure.¹⁸⁰ Finally, over the 1970s the atolls, like many of the Pacific Islands,

¹⁷⁶ Earlier papers on the study took into account all participants over twenty years when assessing prevalence rates so the numbers appeared lower; there were very few cases found in those under thirty-five years old but a sharp rise thereafter. As far as I can tell, the increasing susceptibility to diabetes with age was allowed for in published results that demonstrated the relationship between obesity and diabetes.

¹⁷⁷ Prior, ‘Migration and Chronic Disease’, p.363.

¹⁷⁸ Østbye, et al., pp.585–6.

¹⁷⁹ Wessen, ‘Ian Prior and the Tokelau Island Migrant Studies’, p.21.

¹⁸⁰ *Ibid.*, p.22; A. Hooper and J. Huntsman, ‘The Migrants and their Communities’, in Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, pp.126–31.

experienced rapid social changes.¹⁸¹ The New Zealand government financed new infrastructure and strengthened the public services which generated employment and increased availability of Western foods and cultural products.¹⁸² Both the Tokelauans who stayed in their homeland and those who came to New Zealand got to enjoy increased access to Western labour-saving devices, more sugary foods and alcohol, which apparently manifested itself in weight gain and diabetes.¹⁸³

Nevertheless, the TIMS researchers determined ‘that something in the migrants’ lifestyle enhanced the risk of developing diabetes’.¹⁸⁴ Prior found the age-standardised relative risk of diabetes development in migrants over non-migrants was 1.9 per cent for women and 1.5 per cent for men. These were very similar to the Maori relative risk figures, despite Maori having much longer exposure to a Westernised environment. The factor most influential in the onset of diabetes was obesity. At the end of the study women in both environments had a mean body weight indicating obesity and migrant men were fast approaching this. For men and women, the higher the level of obesity the more likely they were to have diabetes.¹⁸⁵ Migrants had more obesity at all ages compared to non-migrants and the difference in the prevalence of diabetes between migrants and non-migrants increased at each round. When combined with similar findings on the other conditions and coronary risk factors in the study, ‘the overall hypothesis that migrants would experience an increased burden of chronic disease problems when compared to non-migrants was broadly confirmed’.¹⁸⁶ It appeared that in the space of

¹⁸¹ Richard Taylor, ‘History of Public Health in Pacific Island Countries’, in Milton J. Lewis and Kerry L. MacPherson, eds, *Public Health in Asia and the Pacific: Historical and Comparative Perspectives*, Oxon, 2008, pp.278–94.

¹⁸² A. Hooper and J. Huntsman, ‘Tokelau, New Zealand, and the United Nations: 1948 to 1984’, in Albert E. Wessen, ed., *Migration and Health in a Small Society: The Case of Tokelau*, Oxford, 1992, pp.85–86.

¹⁸³ Østbye, et al., pp.588–9.

¹⁸⁴ Prior, ‘Migration and chronic disease’, p.365.

¹⁸⁵ Ibid. The researchers argued obesity caused by excess calories, irrespective of what foods they came from, was the most important contributor to diabetes. The common suggestion that simple sugar had a qualitative effect on diabetes development was not supported in any of the Wellington studies: see Østbye et al., p.588.

¹⁸⁶ Wessen, ‘Ian Prior and the Tokelau Island Migrant Studies’, p.24.

only fourteen years that Tokelauan migrants bodies showed the consequences of ‘Westernisation’ and those on the atolls were not far behind.

Prior and his team intended their research to point the way for interventions to prevent health problems like diabetes in New Zealand and the Pacific. Some of the direct results were new services and medical facilities, particularly in the Pacific where there were obvious deficiencies. But Prior very clearly, and despite his emphasis on broader environmental influences, saw his research as evidence for promoting individual behavioural change. As early as 1966 Prior and Davidson had argued

The extent of diabetes disclosed, particularly among the New Zealand Maoris, [sic] raises a number of problems which will need to be tackled by long-term measures aimed at influencing the Maori attitude towards food, obesity and exercise... The pattern in the Cook Islanders will also be influenced adversely by increasing exposure to Western material resources and availability of food. The steady influx of Cook Islanders into New Zealand will give them the opportunity to develop the same health and disease pattern of the New Zealand Maoris.¹⁸⁷

Critics of Western epidemiology of non-Western peoples have pointed to the tendency for diseases like diabetes to be cast as a product of failure, either genetically, culturally, or both, to adapt to modern life.¹⁸⁸ While modern life was recognised as creating structural barriers and problems which were difficult for individuals to overcome, the underlying assumption was that the process of change was inevitable, natural and predictable.¹⁸⁹ This appeared to be Prior’s assumption in the mid-1970s when he wrote of the Maori and, increasingly, Pacific peoples’ higher risk status for ‘diseases of maladaptation’. He went on to argue that the major health problems facing New Zealand were ‘related to areas in which the individual has choice’, but that more research was needed on the ‘applicability and acceptability’ of the

¹⁸⁷ Prior and Davidson, p.382.

¹⁸⁸ Nancy J. Pollock, ‘Social Fattening Patterns in the Pacific – the Positive Side of Obesity. A Nauru Case Study’ in Igor de Garine and Nancy J. Pollock, eds, *Social Aspects of Obesity*, Luxembourg, 1995, pp.87–109; Mariana Leal Ferreira and Gretchen Chelsky Lang, eds, *Indigenous Peoples and Diabetes: Community Empowerment and Wellness*, Durham, NC, 2006.

¹⁸⁹ Mahuika, pp.133–49.

‘scientific facts’ to different ethnic groups in New Zealand or else ‘prevention will never occur’.¹⁹⁰

Spanning fourteen years, the TIMS represented a major collaborative, transnational endeavour to understand whether, in Prior’s words, chronic diseases like diabetes were ‘the price of civilization’.¹⁹¹ Augmenting the findings of the earlier Maori studies, TIMS provided persuasive epidemiological evidence that obesity was the key modifiable risk factor for diabetes. The lifestyle of the high-risk overweight Maori and Pacific people would become central to public health approaches to diabetes in the 1980s and 1990s.

Conclusion

In the early twentieth century, physicians and other observers noted an increase in diabetes in New Zealand. As life expectancy rose, and infectious diseases and infant mortality declined, chronic diseases like diabetes appeared more commonplace. However, to those at the time, this was not the only explanation of why they saw more diabetes. Developments in diagnosis and treatment made diabetes more visible to the medical profession. Some questioned whether the arrival of an effective treatment, insulin, was allowing more people with diabetes to reproduce and pass on the condition. While many looked on these transformations favourably as the fruits of modern scientific medicine, others expressed anxieties that diabetes was one of the deleterious effects of modern ‘civilised’ lifestyles. The presence of such uncertainty was a result of interpreting statistics about a largely hidden disease with multiple expressions and complications. This problem was not unique to New Zealand as we see by comparing New Zealand debates with Mauck’s discussion of diabetes epidemiology in the United States during the same period.

¹⁹⁰ Prior ‘Polynesian Health’, p.111.

¹⁹¹ Prior, ‘The price of civilization’.

Efforts to assess and account for diabetes in New Zealand were part of an international trend. Early New Zealand researchers looked particularly to the United States, which had the highest reported rates of diabetes in the world, to interpret, compare and make predictions about New Zealand's diabetes statistics. With the advent of new epidemiological methods for understanding chronic diseases, the 'hidden' nature of diabetes in the community drew international attention to the disorder and its comparative prevalence. It was, however, a local Health Department report revealing the high mortality and morbidity of Maori from a range of chronic diseases which inspired the first population-based research into diabetes in New Zealand in the 1960s. The Wellington Hospital Medical (from 1970, Epidemiological) Unit's prospective surveys constituted 'natural experiments' which, echoing Stegman's findings in the American Southwest, advanced scientific knowledge as they highlighted a public health crisis of diabetes in Maori and Pacific communities; by the 1980s Maori and Pacific people became primary 'at-risk' groups for preventive intervention. In the process, New Zealand researchers joined an international network in the burgeoning field of chronic disease epidemiology. Moreover, the WHO became a major influence on New Zealand's responses to diabetes in the latter twentieth century.

For most of the twentieth century, the contention that diabetes was a disease of civilisation was a dominant explanation of statistical and epidemiological evidence linking diabetes to obesity. In the early period commentators made claims based on personal clinical experience and potential statistical correlations, and laid blame for the rise of diabetes on either scientific progress or 'overindulgence' in 'an artificial way of living' – both features of the affluent, modern societies that few would want reversed. Their suggested solution thus was not to reform the social and economic structures of 'civilisation' but to reform 'the foolish fat man or woman' and encourage early diagnosis; detection drives would be the predominant public

health strategy of the 1960s.¹⁹² Similarly, the epidemiological investigations into the ‘Westernisation’ of Maori and Pacific people in the 1960s and 1970s saw the social and economic changes these communities were undergoing as unstoppable. In emphasising these environmental factors, Prior and his team saw the potential for preventive intervention, but indicated this would take the form of influencing the individual ‘in the direction of prudent healthy living’.¹⁹³ This focus on influencing individual behaviour would dominate public health approaches to diabetes in the latter decades of the twentieth century. However, prior to this, in the mid-twentieth century, people with diabetes were organising to demonstrate they were behaving responsibly; the next chapter examines the reasons why.

¹⁹² See Chapter Three

¹⁹³ Prior ‘Polynesian Health’, p.115.

CHAPTER TWO

‘The common purpose should be to assist diabetics to help themselves’: diabetic associations, c.1942–84

What are diabetic associations? We know that they are composed of lay and medical people either afflicted by or interested in diabetes. The common purpose should be to assist diabetics to help themselves... Unfortunately this is not appreciated by much of the public. There is a general feeling that diabetic associations are “bludgers” on the public purse. There is also a feeling that diabetic associations wish to supplant physicians... It is not appreciated that our true field is ancillary.¹

In 1964 the editor of the *N.Z. Diabetic Review*, John Reid, called on people with diabetes to drop their morbid attitudes and adopt ‘as a creed’ the motto ‘self-help not self-pity’. He argued that if people with diabetes took responsibility for themselves they could improve their own welfare and the community’s attitude towards them. Written two years after the formation of the Diabetic Association of New Zealand (DANZ), a national co-ordinating organisation for local societies of people with diabetes and their families, this article raises interesting questions about the social experience of diabetes and the role of voluntary organisations. What was behind the negative attitudes associated with diabetes and how did diabetic societies try to overcome these? How did this voluntary activity relate to publicly provided health and welfare services? And what was the relationship between lay involvement and the medical profession?

This chapter addresses these questions by examining the origins and welfare activities of diabetes organisations in New Zealand from the 1940s to the early 1980s. Lay diabetes societies, which provided peer support, education and advocacy, appeared throughout the Western world during this period. Many historical accounts of these groups are

¹ J.S. Reid, ‘Using public relations to help’, *N.Z. Diabetic Review*, May 1964, pp.3–5.

commemorative and individualised.² Other studies have portrayed diabetes societies as forerunners to medical professionals' wider adoption of patient education in late twentieth century chronic disease management.³ While some histories have discussed lay involvement in social advocacy campaigns against employment and insurance discrimination, others have considered diabetes associations to have been dominated by the professional interests of paternalistic physicians who served as advisors.⁴ Taking a broader perspective on diabetes associations' social advocacy, this chapter will argue that these organisations' relationship to welfare provision are also crucial for understanding their growth in New Zealand in the mid-twentieth century. Additionally, the following discussion investigates whether characterisations of diabetes associations as physician-controlled are applicable to the New Zealand case. Drawing on recent histories of voluntary welfare in New Zealand, the chapter will highlight the ways in which these organisations employed an ideology of individual responsibility within increasingly complex relationships with government and medical professionals during the period of the classic welfare state.

² Bee Dawson, *Dedicated to Diabetes: Diabetes New Zealand, 1962–2002*, Wellington, 2002; Gordon Rodger, *Diabetes Northland: A Brief History of the First 25 Years, 1979–2004*, Whangarei 2004; Margaret Jamieson, *History of Diabetes Nelson Incorporated: Formerly, The Diabetic Association of New Zealand (Nelson Division), 1957–2005*, Nelson, 2005.

³ Leo P. Krall, 'The history of diabetes lay associations', *Patient Education and Counselling*, 26, 1995, pp.285–91; Helen Valier and Roberta Bivins, 'Organization, Ethnicity and the British National Health Service', in Jennifer Stanton, ed., *Innovations in Health and Medicine: Diffusion and Resistance in the Twentieth Century*, London, 2002, pp.37–63. See Chapter Four of this thesis for a discussion late twentieth century patient education in New Zealand.

⁴ F.I.R. Martin discussed Australian societies' efforts against employment and insurance discrimination: F.I.R. Martin, *A History of Diabetes in Australia*, Melbourne, 1998, pp.47–56. For accounts that suggest the dominance of physicians, see Martin D. Moore, 'A Question of Control? Managing Diabetes and its Professionals in Britain, 1910–1994', PhD thesis, University of Warwick, 2014, pp.66–133; and Robert Tattersall, *Diabetes: The Biography*, Oxford, 2009, p.85. The ADA was a physician-only organisation until 1970, which led Jeremy Greene to describe it as paternalistic: Jeremy A. Greene, *Prescribing by Numbers: Drugs and the Definition of Disease*, Baltimore, 2007, pp.87–88. Aaron Mauck, however, presented patient-volunteer involvement in local affiliate societies in the 1940s and 1950s as characterised by willing participants who accepted the attitudinal ideals of self-control the ADA promoted: Aaron Pascal Mauck, 'Managing Care: The History of Diabetes Management in Twentieth Century America', PhD dissertation, Harvard University, 2010, pp.192–244.

‘Matters of vital interest to all Diabetics’ future welfare’

In March 1942, Mr W.H. Caldwell placed an advertisement in the *Auckland Star* for a meeting to discuss ‘matters of vital interest to all Diabetics future welfare’. This followed a series of letters to the newspaper over the previous few weeks that had expressed concern about ‘the plight of diabetics ... should a state of emergency arise’ which might threaten insulin supplies. Caldwell, who had two insulin injections a day to treat his diabetes, implored, ‘Something may be done if all diabetics will get together immediately ... and band themselves into a diabetic community’.⁵ The meeting resulted in New Zealand’s first organisation of people with diabetes, the New Zealand Diabetic Welfare Association (NZDWA).⁶

The welfare of people with diabetes had become a public concern two decades earlier with the introduction of insulin treatment. Initially, insulin was only available to inpatients at the public hospitals in New Zealand’s four main centres. Largely funded through local and central government taxation, with advances in medicine and safety, public hospitals in the 1920s were losing their reputation as places for the destitute, but patients still had to pay fees or apply for charitable admission.⁷ From October 1923, as more supplies arrived, the Health Department would supply any medical practitioner with insulin to treat patients who had had an analysis of their blood.⁸ Patients could require up to fifty units of insulin per day; thus, at 2d per unit, insulin was expensive. Only the wealthy or those prepared to rely on charitable aid could afford what was fast becoming recognised as a long-term treatment.⁹ The South

⁵ ‘Diabetics’, *Auckland Star*, 12 March 1942.

⁶ Originally called the Auckland Diabetic Welfare Association, the organisation changed its name to the NZDWA in May 1942, as it claimed membership as far afield as Gore: see ‘Diabetic Association’, *New Zealand Herald*, 8 May 1942.

⁷ Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, Wellington, 2007, p.91.

⁸ ‘Supplies of insulin’, *Evening Post*, 6 October 1923.

⁹ ‘Insulin treatment’ *Auckland Star*, 8 January 1924.

Canterbury Hospital Board, according to one newspaper report, considered that, ‘The use of insulin in the hospital was a delicate question. Once it was given to a patient it had to be continued through life, and this would mean the Board would be faced with an enormous expense every year.’¹⁰ Wellington Hospital, where doctors were making ‘special studies’ of insulin, claimed it would not deny treatment to any person with diabetes.¹¹ Strong demand soon saw prices drop internationally and the Health Department negotiated with its Australian supplier, Commonwealth Serum Laboratories, for lower prices. From July 1924, public hospitals paid 1/2d per unit, however patient numbers were increasing.¹² In light of ‘much comment’ in the press, the Director General of Health, Thomas Valintine, wrote to Hospital Boards asking how much they charged patients ‘for the treatment in question’.¹³ All of the Boards replied that they only charged maintenance costs for patients outside their districts, with the costs recovered from the Board where the patient lived. This meant poorer people with diabetes could access free insulin while in hospital. Yet treatment was increasingly moving outside the hospital.

Many physicians worried about how patients would cope with continuing insulin treatment outside the hospital. Historian Elizabeth Lane Furdell found that in Britain some doctors believed people with diabetes might go on ‘hysterical bouts of over-eating’, so resisted giving their limited supplies of insulin to ‘ignorant’ patients who they did not trust to test their urine regularly or eat correctly.¹⁴ New Zealand doctors could express similar attitudes, as Wellington’s Dr D. MacDonald Wilson noted, ‘Treatment was not easy... The patient must go

¹⁰ ‘Supply of insulin – Hospital Board’s position’, *Timaru Herald*, 21 February 1924.

¹¹ ‘Insulin treatment’

¹² ‘Lower prices – insulin developments’, *Lyttleton Times*, 24 May 1924.

¹³ Valintine to Auckland Hospital Board, Wellington Hospital Board, North Canterbury Hospital Board and Otago Hospital Board, 31 July 1924, Diseases – Diabetes – Insulin, 1924–35, ADBZ 16163 H1 1959/ 131/20/1 (3834), Archives New Zealand, Wellington (ANZW).

¹⁴ Elizabeth Lane Furdell, *Fatal Thirst: Diabetes in Britain until Insulin*, Leiden, 2009, p.155.

through training. The whole problem was that they had too few intelligent patients.’¹⁵

Christchurch biochemist Robert Roy Milligan, on the other hand, was more optimistic about treating people with diabetes as outpatients because it would allow them to ‘go about their usual vocations’.¹⁶ One of the perceived benefits of insulin was that it might initiate or restore the productivity of people with diabetes, with many being able to work or live almost normal, albeit highly disciplined lives.¹⁷

Nevertheless, insulin treatment meant people with diabetes and their families faced an ongoing cost, which not all could afford, particularly during the Depression. In November 1929, a desperate father wrote to the Health Department requesting insulin to treat his son, as his needs were ‘a big expense to a working man’.¹⁸ Valintine gave the father a list of the different brands of insulin and their prices and suggested that if the costs were too much he should place his ‘position before the Hospital Board’.¹⁹ By 1934 this situation remained, although the new Director-General of Health Dr Michael Watt requested that, ‘In view of the expense involved to a diabetic being of a continuous nature’ that sales of insulin through Hospital Boards ‘should simply cover costs’. Ultimately, people with diabetes were still responsible to meet these costs or apply for charitable aid.

On top of the financial costs associated with diabetes, stigma and public misconceptions meant people with the disorder could face other social problems. In the 1920s and 1930s, with so little understood about the mechanism of insulin’s action, physicians and people with diabetes could have difficulties managing insulin dosage. Too much insulin could lead to hypoglycaemia. Members of the public could mistake people suffering from low blood sugars

¹⁵ ‘Insulin – its use in cases of diabetes’, *Dominion*, 9 April 1924.

¹⁶ ‘Insulin cure’, *Lyttleton Times*, 7 August 1924.

¹⁷ A good example of this is ‘Back to life’, *NZ Truth*, 5 January 1924.

¹⁸ ‘A.M.’ to Health Department, 12 November 1929, ADBZ 16163 H1 1959/ 131/20/1 (3834), ANZW.

¹⁹ Valintine to ‘A.M.’, 16 November 1929, ADBZ 16163 H1 1959/ 131/20/1 (3834), ANZW.

for being drunk, and did not know how to deal with those who lost consciousness.²⁰ A lack of public awareness contributed to the stigma associated with diabetes and, as Aaron Mauck noted in his history of diabetes management in the United States, there was popular belief the disorder was ‘*inherently* dangerous’.²¹ Such misperceptions had real implications for people with diabetes, even if they were not on insulin: some suffered from employment discrimination; others were unable to obtain life or health insurance until well into the second half of the twentieth century. Meanwhile, dietary restrictions caused difficulties with travelling and eating out. These social challenges for people with diabetes were similar around the Western world.²²

Internationally, doctors’ and patients’ concerns about the social justice aspects of insulin underpinned the charitable origins of the first diabetes associations. Dr Ernesto Roma founded the Portuguese Association for the Protection of Poor People with Diabetes (now the Portuguese Diabetes Association) in Lisbon in 1926. While in the United States in 1922, Roma had seen the life-saving use of insulin at the Joslin Clinic in Boston. On returning to Portugal, and in the absence of state assistance for the needy who required insulin, Roma brought together a group of wealthy benefactors and people with diabetes into an association to provide economic and social support.²³ In the early 1930s Dr R.D. Lawrence, who had diabetes himself, and his patient, the author H.G. Wells, appealed to other ‘rich and grateful diabetic patients’ in Britain to raise money for a diabetes department at Knox College Hospital.²⁴ The success of this appeal inspired the foundation of the British Diabetic Association (BDA) in 1934. Open to, as Lawrence put it, ‘diabetics from all ranges of life’,

²⁰ For example, see ‘Mistaken for drunkenness’, *N.Z. Truth*, 6 November 1930.

²¹ Mauck, p.22. Italics in original.

²² James G.L. Jackson, ‘R.D. Lawrence and the formation of the Diabetic Association’, *Diabetic Medicine*, 13, 1, 1996, pp.18–22; Mauck, pp.192–244; Martin, pp.47–56.

²³ João Manuel Valente Nabais, ‘Care, education, protection – the *Associação Protectora dos Diabéticos de Portugal* goes from strength to strength’, *Diabetes Voice*, 57, 1, April 2012, pp.31–33.

²⁴ R.D. Lawrence, ‘The beginnings of the Diabetic Association in England’, *Diabetes*, 1, 5, 1952, p.421.

the BDA's draft constitution indicated it was 'organized for service and not for profit ... for diabetics and those interested in diabetes for mutual aid and benefit' and that it 'act as an authoritative body to safeguard the social and economic interests of diabetics'.²⁵ Thus, a major focus of these early diabetes associations was to ensure insulin, medical and social assistance to all who needed it, regardless of their income.

In New Zealand, many felt the government should take more responsibility to ensure that the vulnerable, including people with diabetes, were not subject to the whims of charity. The Depression of the early 1930s had highlighted the inadequacies of – and public discontent with – the country's ad hoc health and welfare provision.²⁶ In March 1935, 'Sympathiser' wrote to the *Christchurch Times*, applauding British philanthropist Viscount Nuffield's donation to the newly established Crippled Children's Society. He or she stated, 'Now, Sir, I would like to see something done to assist diabetes.' 'Sympathiser' thought the government should assist those who required insulin and expensive diabetic foods, as well as provide special clinics.²⁷

The first Labour government came to power in November 1935 having campaigned to introduce a comprehensive welfare system based on the principles of universalism and citizens' entitlement to a decent standard of living. Though their initial plans were modified and delayed following difficulties securing funding and political support, Labour succeeded in replacing what historian Margaret McClure has described as the 'haphazard, niggardly pension system of the early twentieth century'.²⁸ Labour introduced legislation, notably the

²⁵ Ibid.; Jackson, p.18. Martin Moore notes that the BDA formation was intimately bound up with physicians' promotion of specialist hospital clinics as the basis of good diabetes care: pp.63–133.

²⁶ Margaret McClure, *A Civilised Community: A History of Social Security in New Zealand, 1898–1998*, Auckland, 1998, pp.56–58.

²⁷ *Christchurch Times*, 15 March 1935.

²⁸ McClure, p.82.

Social Security Act of 1938, which established new or extended support (pensions were now called benefits) for a range of categories of need, universal superannuation and health care. The government provided these measures as a right of citizenship in order to overcome the stigma of charitable aid.²⁹

Some people with diabetes adopted the rhetoric of citizenship entitlement to bring attention to public provision for their welfare. In 1936, prior to Labour's introduction of invalid and unemployment benefits, Ronald Lawrence Morrison smashed an Auckland Hospital Board (AHB) window so the police would arrest him. He did this to protest that his diabetes rendered him ineligible for unemployment sustenance; the authorities had told him he must instead be a charge on the AHB. He pleaded guilty, refusing the Salvation Army's offer of assistance because 'he did not care for charity'.³⁰ Charity and welfare had distinct emotional resonance for Morrison. A few months later Morrison was in court again for breaking the glass of a telephone box. On this occasion, he complained that while an able-bodied unemployed man could claim 17s 6d per week, he could get only 10s per week from the AHB.³¹ Six months later he again smashed a telephone box and reiterated his protest: 'I don't want charity, I want justice'.³² A former engineer, Morrison claimed he could work but was unable to keep a job because he required daily treatment. He apparently had the Prime Minister, Michael Joseph Savage, investigating his case.³³ In 1938 he faced another mischief charge after smashing yet another telephone box. He alleged that the government had refused him an invalid's benefit and that he should be entitled to an unemployment benefit.³⁴ Eventually Morrison did receive an invalid's benefit, but, frustrated by a delay in his

²⁹ Ibid., p.83.

³⁰ 'Man seeks arrest', *New Zealand Herald*, 23 June 1936.

³¹ 'Destructive mood', *Evening Post*, 29 December 1936.

³² 'Wants justice', *Auckland Star*, 8 September 1937.

³³ 'Mischief charge', *New Zealand Herald*, 9 September 1937.

³⁴ 'Backhanders', *Auckland Star*, p.11.

payments, he went to the Auckland central police station and smashed an electric light. He reasoned that his benefit was still not enough for his diabetic foods and that he would prefer jail than ‘going home and imposing on my mother’, or returning to the hospital.³⁵ Though he provides an extreme example, Morrison’s case illustrates some of the difficulties people with diabetes faced negotiating the welfare system.

Others chose to bring their plight to the attention of authorities within the confines of the law. In April 1937, an anxious Christchurch man wrote to the Minister of Health, Peter Fraser. The man had a thirteen-year-old daughter and another member of his household suffering from diabetes and wanted the government to consider insulin in its national health plans. He asked Fraser that insulin be ‘priced in accordance with a wage earner’s purse’. His greatest fear, however, was ‘that should world conditions become disturbed the supply would either become not available or erratic, and this terrible complaint does not allow intermittent treatment’.³⁶ The Acting Director-General of Health, Dr Robert Shore, replied that there was no reason to believe the Australian suppliers could not meet New Zealand’s demands if the ‘remote event’ of world war occurred.³⁷

In many countries, the advent of the Second World War in 1939 brought serious concerns about the availability of insulin and food for people with diabetes. Until the 1980s, insulin was made from animal pancreases, which meant manufacturers relied on stockpiles of the glands from abattoirs. In Britain, U-boat activity threatened these supplies and air raids destroyed stocks.³⁸ Britain had only enough pancreases to meet domestic needs and suffered distribution problems during the war. Rationing was another concern for people with diabetes.

³⁵ ‘Gaol preferred’, *New Zealand Herald*, 23 May 1939.

³⁶ ‘T.N.’ to Fraser, 21 April 1937, Diseases – Diabetes – Insulin, 1935–38, ADBZ 16163 H1 1959/ 131/20/1 (3835), ANZW.

³⁷ Shore to ‘T.N.’, 3 May 1937, ADBZ 16163 H1 1959/ 131/20/1 (3835), ANZW.

³⁸ Furdell, p.157.

The BDA successfully lobbied the Ministry of Food to allow people with diabetes extra fat rations and to swap their sugar ration for an extra meat ration. In the United States the newly formed (1940) American Diabetes Association, which unlike the BDA was only open to physicians, followed the British example on subjects including insulin allocation, emergency treatment and food rations.³⁹ Both Belgium and Sweden also established diabetetic associations during the war, with an aim of ensuring access to medical supplies.⁴⁰

In New Zealand, the Health Department had concerns about maintaining adequate insulin supplies. New Zealand imported most of its insulin from Australia, but some also came from Britain and the United States for those who could not tolerate the Australian brand.⁴¹ By 1942, the United States refused to export supplies to New Zealand, and British supplies could be infrequent, waylaid or damaged. The Department looked into manufacturing insulin in New Zealand, but determined that this would be too difficult due to the personnel and equipment that would be involved.⁴² Parliament discussed the situation in June 1942; the Minister of Health, Arnold Nordmeyer, reassured the House that his Department held enough supplies to last several months and people with diabetes could draw up to four months' worth on one prescription.⁴³ These assurances overlooked the greater demand for Commonwealth stocks as other suppliers stopped exporting and produce was lost in enemy action or damaged during transportation. Urgent telegram orders and insurance claims filled the Health Department files. In 1943, the Department entered protracted negotiations with

³⁹ Cecil Striker, 'The early history of the American Diabetes Association', *Diabetes*, 5, 4, 1956, p.320.

⁴⁰ Jackson, pp.20–21.

⁴¹ The Department of Health handled 80 per cent of all insulin sales in New Zealand and 88 per cent of this it sourced from Commonwealth Serum Laboratories: see Director-General of Health to Official Secretary of the High Commission for New Zealand, 4 January 1945, Diseases – Diabetes, 1942–46, ADBZ H1 1406/ 131/20/1 (16133), ANZW.

⁴² These discussions continued well after the war as insulin demand continued to grow and shortages were a worldwide problem.

⁴³ *New Zealand Parliamentary Debates* (NZPD), June 1942, p.399.

Commonwealth Serum Laboratories over the supply and price of New Zealand-sourced pancreases, as the company claimed to be unable to meet demand.⁴⁴

Concern over insulin supplies led to the formation of the New Zealand Diabetic Welfare Association (NZDWA) in 1942. As British and American brands of insulin became less available, some people with diabetes became anxious about a complete shortage. Mr W.H. Caldwell wrote to Nordmeyer claiming that doctors and chemists were telling their patients that supplies were scarce. Unhappy with Nordmeyer's response, which downplayed people with diabetes' concerns by suggesting that they were only the concerns of a noisy few – Nordmeyer suggested that users of a particular brand which was no longer available were causing 'a great deal of agitation' – Caldwell organised a public meeting in Auckland 'to decide what further action should be taken'.⁴⁵ The meeting, held on 31 March 1942, drew enough people to establish the NZDWA. It elected Caldwell as President and a committee 'to consider the maintenance of supplies of insulin'. A representative of the Auckland Hospital Diabetic Clinic assured those in attendance that they could obtain supplies from the clinic if needed, and spoke of 'precautionary measures diabetics should take against a possible day of enemy raiding'.⁴⁶ On 23 May, Caldwell met Nordmeyer in Auckland to discuss the insulin situation. Nordmeyer was emphatic that 'the Government had and is doing all that is humanly possible to obtain supplies of insulin' and that Australia 'will stand by us' should there be an emergency.⁴⁷ This appeared to have soothed the NZDWA's concerns until another supply issue arose in 1945 over a shortage of insulin bottles. The Association negotiated with

⁴⁴ ADBZ H1 1406/ 131/20/1 (16133), ANZW.

⁴⁵ 'Supplies of insulin', *New Zealand Herald*, 28 March 1942.

⁴⁶ 'Diabetics' welfare', *New Zealand Herald*, 1 April 1942.

⁴⁷ 'Minutes of a deputation from the N.Z. Diabetic Welfare Association (represented by Mr. Caldwell) heard by the Hon. A.H. Nordmeyer, 23 May 1942', Diseases – Diabetes, 1941–65 ADBZ 16163 H1 164/ 131/20 (30435), ANZW.

Nordmeyer for the Health Department to pay freight for people who sent in their empty insulin bottles and rubber stoppers for reuse.⁴⁸

Another issue the NZDWA brought up with Nordmeyer was the cost of prescriptions for insulin. Caldwell relayed ‘that several doctors in Auckland had been charging fees for writing out the prescriptions for the [sic] insulin’. Nordmeyer responded that he was aware ‘that some doctors charged and some did not, but even if they did, it was in the interest of the patient that they have a check-up every few months’.⁴⁹ The organised medical profession had staunchly fought against what its leadership saw as socialised medicine under Labour’s Social Security Act, arguing that it undermined doctor-patient relationships.⁵⁰ Public hospital inpatient treatment was free from 1939 but it took until 1941 for the government to reach a compromise with the profession over general practitioners’ services. These were now substantially subsidised, but many doctors continued to take a part charge from the patient, a situation that would be formalised in a 1949 amendment to the Social Security Act that allowed doctors to charge an unspecified token fee.⁵¹ Similarly, the New Zealand Branch of the British Medical Association (NZBMA) held up the introduction of pharmaceutical benefits and forced the government to accept doctors’ autonomy to prescribe as they saw fit, without restriction. Pharmaceutical benefits came into force in May 1941.⁵² So while insulin was now free to the patient, obtaining prescriptions for it might not be. As Nordmeyer’s response to Caldwell

⁴⁸ ‘Empty insulin bottles’, *Auckland Star*, 28 July 1945. Minor supply issues caused by the war continued into 1946, but there was very little discussion in the press: see Diseases – Diabetes – Insulin, 1946–62, ADBZ 16163 H1 1106/ 131/20/1 (34569), ANZW.

⁴⁹ ‘Minutes of deputation from the N.Z. Diabetic Welfare Association’.

⁵⁰ D.G. Bolitho, ‘Some financial and medico-political aspects of the New Zealand medical profession’s reaction to the introduction of Social Security’, *New Zealand Journal of History*, 18, 1, 1984, pp.34–49; Elizabeth Hanson, *The Politics of Social Security: The 1938 Act and Some Later Developments*, Auckland, 1980, pp.98–132.

⁵¹ Iain Hay, *The Caring Commodity: The Provision of Health Care in New Zealand*, Auckland, 1989, pp.139–43.

⁵² Astrid Baker, ‘Paying the Price: Pharmaceutical Benefits and Government Policy-Making, 1938–1986’, in Linda Bryder and Derek A. Dow, *New Countries and Old Medicine: Proceedings of an International Conference on the History of Medicine and Health*, Auckland, 1994, p.119.

suggested, people with diabetes would still shoulder some responsibility for their ongoing health care costs.

Through its own welfare and educational activities, the NZDWA attempted to show that people with diabetes were self-reliant, productive members of society deserving greater support. At its first annual meeting on 31 May 1943, the NZDWA ‘proposed, in time, to arrange for boarding houses in town and country catering for diabetics and to establish special restaurants, clinics and nursing homes’.⁵³ By the second annual meeting, it was discussing the production of a ‘diabetic journal’.⁵⁴ Both these suggestions had precedents in the activities and constitution of the BDA. The NZDWA did not achieve either of these goals but did form a committee to visit sick members in their homes or hospital, and a ‘ladies social committee’ to undertake fundraising.⁵⁵ It had Dr Elaine Gurr, a respected Auckland general practitioner, serve as patron and a ready source of health advice.⁵⁶ She spoke several times, along with other local and overseas health professionals, in a monthly public lecture programme that covered both medical and social ‘matters of immediate interest to diabetics’.⁵⁷ For example, Auckland neurosurgeon Dr Howard Gaudin, while speaking on the latest surgical techniques, also brought up ‘the question of employment of diabetics’, arguing that there was no reason for employers not to hire people with diabetes.⁵⁸ The *Auckland Star* reported that members looked forward to these lectures and that their enthusiasm was a sign that ‘sufferers of diabetes are fully aware of their responsibilities to the community and also their desire to take

⁵³ ‘Diabetic Association’, *Auckland Star*, 1 June 1943.

⁵⁴ ‘Diabetic Association’, *Auckland Star*, 3 April 1944.

⁵⁵ ‘Diabetic welfare’, *Auckland Star*, 26 March 1945.

⁵⁶ For more on Gurr, see Margaret D. Maxwell, *Women Doctors in New Zealand: An Historical Perspective, 1921–1986*, Auckland, 1990, pp.122–26; and Philippa Mein Smith, ‘Gurr, Eily Elaine’, from the Dictionary of New Zealand Biography. Te Ara – the Encyclopaedia of New Zealand, updated 2 October 2013, URL: <http://www.TeAra.govt.nz/en/biographies/5g23/gurr-eily-elaine>, accessed 7 June 2014.

⁵⁷ ‘N.Z. Diabetics’, *Auckland Star*, 22 March 1943. Copies of the lectures were sent to members outside of Auckland.

⁵⁸ ‘Surgical advances’, *Auckland Star*, 1 October 1943.

an active part in the event of any emergency'.⁵⁹ The NZDWA, however, failed to maintain its momentum. After the wartime anxieties particular to people with diabetes had subsided, it appears to have been quickly disbanded.⁶⁰

Thus, the short-lived NZDWA arose as a voluntary sector response to the threat war conditions posed to people with diabetes. It was not without overseas precedent and reflected long-standing concerns about the charitable provision of treatment and social challenges that people with diabetes faced. The Association served as an advocate for people with diabetes to ensure they received what they believed they were entitled to, during a time when the government was taking more responsibility for public welfare and health services. Nevertheless, its underlying premise was that people with diabetes should look out for their own welfare as responsible citizens.

'Little interest has been shown in diabetics by outsiders'

In January 1958, the *Christchurch Star-Sun* carried the headline 'Diabetics neglected in N.Z.'. The president of the fledgling Christchurch Diabetics' Association, Mr C. Maitland Sheppard, who had diabetes himself, claimed that, in not providing vital equipment, 'the Government attitude to diabetics in New Zealand is "nothing short of gross negligence"', and that 'little interest has been shown in diabetics by outsiders'.⁶¹ From the late 1950s, following developments in diabetes advocacy overseas, people with diabetes in New Zealand were again organising around common concerns about their welfare, and finding ways to help themselves, through a journal, children's camps and by supporting research.

⁵⁹ Ibid.

⁶⁰ The last primary source mentioning the NZDWA I have found was a newspaper report in December 1945. An article on the history of the Auckland Diabetic Society, formed in 1958, mentioned an earlier organisation (presumably the NZDWA) 'had fallen through': Marguerite Durling, 'Diabetes NZ Auckland Inc. Celebrating the Past, Shaping the Future', *Dia-log*, Spring 2008, p.12.

⁶¹ 'Diabetics neglected in N.Z. – Mr Sheppard', *Christchurch Star Sun*, 10 January 1958.

Historians have increasingly challenged a grand narrative in the historiography of social welfare in New Zealand which has asserted that the state occupied an increasing – and eventually all-encompassing – role from the post-war period to the Fourth Labour government (1984). Many have done so by demonstrating the continued importance of the voluntary sector over this period.⁶² Linda Bryder, for example, has shown how the Plunket Society's maternalism, its growing status as a national icon, and the public's 'belief in the virtues of voluntarism', meant that both Labour and National governments supported its continued dominance role providing infant welfare services in the 1940s and 1950s.⁶³ Margaret Tennant has noted that with the early welfare state's focus on young families came concerns that government largesse was not reaching vulnerable groups like the elderly or disabled, which became important growth areas for the voluntary sectors.⁶⁴ These developments created inconsistencies in the welfare state, which, combined with the new needs and identities emerging with the social rights movements of the 1960s and 1970s, provided space for 'a new generation of voluntary organisations'.⁶⁵ The numbers and types of non-governmental organisations multiplied. Some were pressure groups calling for greater government action, some saw themselves as alternative service providers, and others as mediators between their consumer-members and the state. They responded to grassroots concerns, but these groups were often also following overseas examples.⁶⁶

⁶² Margaret Tennant, 'Mixed Economy or Moving Frontier? Welfare, the Voluntary Sector and Government', in Bronwyn Dalley and Margaret Tennant, eds, *Past Judgement: Social Policy in New Zealand History*, Wellington, 2004, pp.39–56. This grand narrative was a progressive one about an increasingly humanitarian society witnessed in the rise of the welfare state or, alternatively, a social control interpretation about omnipresent state power. While the latter tended to reflect the politics of the radical left, it also became part of a neoliberal narrative seen in romanticised accounts of a golden era of charity before the welfare state, such as in David Green, *From Welfare State to Civil Society: Welfare that Works in New Zealand*, Wellington, 1996.

⁶³ Linda Bryder, 'Plunket's Secret Army': The Royal New Zealand Plunket Society and the State', in Dalley and Tennant, p.114; Linda Bryder, *A Voice for Mothers: The Plunket Society and Infant Welfare, 1907–2000*, Auckland, 2003.

⁶⁴ Tennant, *The Fabric of Welfare*, pp.144–63.

⁶⁵ *Ibid.*, p.127.

⁶⁶ *Ibid.*, p.123.

After the Second World War, an international network for advancing information on diabetes and the welfare of those with the disorder developed from the interactions between various national diabetes associations that followed the British model. Typically, these associations were like the BDA in being lay-oriented, with a Medical Advisory Committee of diabetes specialists. In June 1949 the Belgian Diabetic Association and BDA's presidents, Dr J.P. Hoet and Dr R.D. Lawrence, convened discussions on shared concerns with seventy-five physicians and patients from eleven different countries. The following year, meeting in Amsterdam, they formed the International Diabetes Federation (IDF).⁶⁷ In 1952, 241 lay and medical representatives from twenty countries attended the First IDF Congress, in Leiden, the Netherlands. In 1956, the Australian state associations (the earliest of which, based in New South Wales, was formed in 1937) federated to join the IDF.⁶⁸

In New Zealand, people with diabetes, aware of these international developments, began setting up their own societies. In May 1956, Maitland Sheppard convened a public meeting which formed the Christchurch Diabetic Society.⁶⁹ Nelson and Dunedin followed suit in 1957. Sheppard told the press that they were endeavouring to build a national association like in Australia so they could join the IDF.⁷⁰ In 1958, a former Auckland mayor, John Luxford, initiated an Auckland branch. Luxford circularised his 'fellow diabetics' to attend a public meeting for the proposed society which, he argued, would be affiliated to the BDA and IDF and thus able to 'serve our cause with the latest and first-hand information on a world wide

⁶⁷ Donald M. Barnett and Leo P. Krall, 'The History of Diabetes', in C. Ronald Kahn, Gordon C. Weir, George L. King, Alan C. Moses, Robert J. Smith and Alan M. Jacobsen, eds, *Joslin's Diabetes Mellitus*, 14th edition, Boston, 2005, p.15.

⁶⁸ Martin, pp.47–49.

⁶⁹ 'History of the Christchurch Diabetes Society', 2012, URL: <http://www.barnabybee.com/chch>, accessed 7 June 2014. The Christchurch Diabetic Society changed its name to the Christchurch Diabetes Society in 1967.

⁷⁰ 'Diabetics neglected in N.Z.'

scale'.⁷¹ New Zealand's local societies set objectives in line with the BDA's constitution for protecting the welfare of people with diabetes and similarly promoted their existence through the local hospital diabetes clinics and chemists, as well as advertisements in the packaging of urine-testing products and in newspapers. By 1962, representatives of seven local societies gathered in Wellington and established the Diabetic Association of New Zealand (DANZ) 'to act as an authoritative and advisory body for New Zealand, to aid those suffering from diabetes'.⁷² Two years later, physicians interested in diabetes organised a Medical Advisory Panel to the DANZ and elected a representative from each of the country's four main centres. Following some administrative delays, in 1965 the DANZ became an associate member (through Australia) of the IDF; it was a full member from 1967.⁷³

In addition to these international influences, the diabetic society movement in New Zealand agitated in favour of New Zealand people with diabetes own grassroots concerns about Social Security entitlements. In the article 'Diabetics Neglected', Sheppard pointed out that the government in Britain and Australia provided free syringes, needles and other equipment, whereas New Zealand provided only insulin and Benedict's solution (used for testing sugar in the urine).⁷⁴ The Nelson Diabetic Society in the late 1950s, and the DANZ in the 1960s, appealed to the Health Department and Ministers of Health to provide people with diabetes syringes and needles under Social Security. These appeals always came at apparently inopportune times and health officials responded with requests for evidence of hardship.⁷⁵ Minister of Health Donald MacKay told the DANZ's 1966 annual meeting that 'the real

⁷¹ J. H. Luxford, 'Important notice to diabetics', June 1958, Medical Services – care of diabetics, 1955–82, ZABV 4638 A1073 198/a 95/1/44 part 1, Archives New Zealand, Auckland (ANZA).

⁷² 'National body forms in 1962', *Diabetes*, Autumn 2009, p.32.

⁷³ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.6, Diabetes New Zealand, Wellington (DNZ); George Vincent to D.W. Beaven, 5 August 1974, D.W. Beaven Papers, Accession #195, 36788, Macmillan Brown Library, Christchurch (MBL).

⁷⁴ 'Diabetics neglected in N.Z.'

⁷⁵ See correspondence in Social Security – proposed benefit to provide diabetics with hypodermic syringes and needles, 1960–78, AAFB 632 W4914 152/ 206/20 (47888), ANZW.

problems' for people with diabetes were 'of a social rather than medical nature'; he referred to getting employment and insurance and made no mention of government provisions.⁷⁶ The Health Department, meanwhile, did not know how many people were on insulin so had difficulties costing policy proposals to take to the Minister. Following results from the 1971 census, which had a question for people with diabetes about their treatment, and collaborations with the DANZ's Medical Advisors, the Health Department proposed that those on insulin should receive up to two free non-disposable syringes and two packs of needles per year.⁷⁷ This did not occur until 1978, when the Department could use a new source of community health funding, derived from a tax on beer and tobacco which the National government had introduced in 1977.⁷⁸

By this stage, however, many people with diabetes favoured more user-friendly disposable syringes, so the DANZ also lobbied for these to be free to users. The Department had issued a directive for hospitals to supply these to people with diabetes at cost in 1975, but Hospital Boards had problems getting supplies, which limited patient access. A similar situation occurred with the syringes available under Social Security after 1978; a Department survey uncovered cumbersome processes for obtaining the syringes and quality issues.⁷⁹ In 1981, the DANZ President, Trevor Gollins, along with its Medical Advisors, joined a Departmental

⁷⁶ Minutes of the Annual General Meeting of the DANZ, 11 June 1965, p.1, DNZ.

⁷⁷ The MRC asked the census authorities to include health related questions following its 1969 report, *Adequacy of Medical Statistics in New Zealand*. The MRC, on advice from Drs Ian Prior and Don Beaven, suggested a question on diabetes and another on smoking but only the former was accepted as 'the question on cigarette smoking was likely to arouse hostility in smokers': Minutes of a Meeting of the Epidemiology Advisory Committee, 9 June 1970, Epidemiology Advisory Committee – minutes, agenda and papers, 1968–77, YCBN 5981 12d ANZA; File note, 'Payment for syringes and needles required by diabetics', AAFB 632 W4914 152/206/20 (47888), ANZW.

⁷⁸ Circular letter to hospitals 1978/43, Social Security – proposed benefit to provide diabetics with hypodermic syringes and needles, 1978–79, ABQU 632 W4415 486/206/26 (50193), ANZW. For more on this new funding, see Chapter Four.

⁷⁹ See correspondence in ABQU 632 W4415 486/206/26 (50193), ANZW.

committee investigating and overseeing the introduction of the new U100 strength insulin.⁸⁰ As this meant the old sized glass syringes would become obsolete, the committee secured one free plastic disposable syringe per week per person (the Medical Panel had recommended two). This was of little comfort for people who did not want to reuse blunt needles, but the National government was not willing to make more concessions while it tried to restrict growth in health funding more generally in the early 1980s.⁸¹

Despite its concerns about inadequate government support for people with diabetes, the DANZ's organisational focus was on self-help. The DANZ's motto was 'self-help not self-pity': National Secretary John Reid, who had adult-onset diabetes and a professional background in public relations, explained to members in 1965 that 'our first success as a diabetic organisation is to get all of our members to realise their own need for balance and moderation in eating and living. They need also to realise the most constructive part of the diabetic life is to help another diabetic'.⁸² At the local level, the diabetic societies published newsletters, held talks and social events. Some of the larger societies ran additional support services: Auckland had a twenty-four hour telephone advice line, while Christchurch employed a voluntary welfare officer from 1971, and a paid field officer from 1977 who worked in the community, visiting people at home and encouraging them to attend meetings and medical appointments. Local societies also played an important role in public health responses to diabetes, organising detection campaigns.⁸³ The diabetic societies operated via voluntary effort and membership subscriptions from which they paid a levy to the DANZ for

⁸⁰ Trevor Gollins, 'Introduction of insulin U100 strength in New Zealand', *N.Z Diabetic Review*, 17, 3, October 1980, pp.3–4. The DANZ collected the old syringes and sent them to developing countries.

⁸¹ Miss Valerie Watson to Minister of Health, Social Security – proposed benefit to provide diabetics with hypodermic syringes and needles, 1980–84, ABQU 632 W4550 42/ 206-26 (56991)

⁸² Reid, 'Using public relations to help', p.5. Reid went on to serve as President from July 1965 until 1968 when he moved to Australia. The origins of this rhetoric came from R.D. Lawrence's popular educational guide for patients and professionals, *The Diabetic Life*, which went through seventeen editions between 1925 and 1965: see Moore, p.84.

⁸³ See Chapter Three.

national activities and sending delegates to IDF meetings; they did not receive government funding until the 1990s, although government agencies supported the DANZ in other ways that will be discussed below.⁸⁴

Like its overseas counterparts, one of the DANZ's most tangible expressions of self-help was its journal, the *N.Z. Diabetic Review*. Containing recipes, advice, the latest research findings and other news, the journal was a key educational service at a time when organised diabetes education within the health services was in its infancy.⁸⁵ It was also a means of identity building, promoting the worth of people with diabetes and motivating group belonging via the theme of personal responsibility. Having diabetes was an identity in the 1960s, illustrated clearly with the common self-labelling as diabetic. A central concern of diabetic associations around the world was dismissing the notion that this was a morbid or dangerous identity; one way they did this was through their journals. Mauck has argued the American Diabetes Association's patient magazine, *Forecast*, used material which exemplified the 'good diabetic' who followed his doctor's advice and maintained control of his disease. The motif and components of the 'good diabetic' suggested to the patient community that they could fight social discrimination through their personal behaviour.⁸⁶ People with diabetes in New Zealand could access this archetype through the *N.Z. Diabetic Review*, which regularly featured excerpts from its overseas counterparts, including *Forecast*. The *N.Z. Diabetic Review* was edited by lay people, however, as were many of its national stories. Articles covered topics such as food labelling, employment and insurance, and emphasised the power of people with diabetes to contribute to the right public image.⁸⁷

⁸⁴ Chapter Six discusses Diabetes New Zealand's (formerly the DANZ) new relationship with government in the 1990s.

⁸⁵ See Chapter Four.

⁸⁶ Mauck, pp.196–207.

⁸⁷ Some good examples are: Reid, 'Using public relations to help' and 'Keeping balanced', *N.Z. Diabetic Review*, 2, 4, May 1964, pp.3–19; R. Kerr, 'Diabetes and work', *N.Z. Diabetic Review*, 3, 4, May 1965, pp.3–7.

It is difficult to gauge the extent to which people with diabetes accepted these messages. The DANZ was a small organisation, growing from around 800 to 2500 over the 1960s and 1970s, yet, in the 1971 census, 17,430 people reported being under treatment for diabetes and epidemiological evidence suggested this figure meant significant underreporting in the census.⁸⁸ The *Review*'s readership, though, may have extended beyond its members through copies at hospital clinics, for example. There is also evidence that some people with diabetes did differentiate between 'good' and 'bad' diabetics. In his opening address to the DANZ's 1973 annual meeting, the President of the Auckland Society, Sir Reginald Savory, 'stated that he could quote his own experience as an example of lack of proper behaviour as a diabetic'.⁸⁹ Several Otago University preventive medicine dissertations, which surveyed people with diabetes, noted that a number of respondents thought discriminatory practices in employment, or elsewhere, were fair for those who did not help themselves.⁹⁰ This sentiment was still around in the early 1980s, as can be seen from meeting minutes. Doug Rattray of the Southland Diabetic Society, who had diabetes himself, asked the DANZ's 1983 annual meeting: 'Why should I have my (life insurance) premiums loaded because some idiot diabetic cannot be bothered learning how to control or even bothering to control their diabetes?'⁹¹

⁸⁸ Membership numbers in the DANZ annual reports, DNZ; Barry Borman, 'Diabetes mellitus morbidity in New Zealand: a geographic perspective', *Social Science and Medicine*, 14 D, 1980, pp.185–9.

⁸⁹ Minutes of the Annual General Meeting of the DANZ, 7 April 1973, p.4, DNZ.

⁹⁰ 'Some of the Medico-Social Aspects of Diabetes', Preventive Medicine Dissertation, University of Otago, 1971; 'The Employment of the Male Diabetic Requiring Insulin', Preventive Medicine Dissertation, University of Otago, 1967; 'Sociological Factors in Diabetes Mellitus', Preventive Medicine Dissertation, University of Otago, 1975; 'Living with Diabetes: a Survey of Experiences of Diabetic Patients', Preventive Medicine Dissertation, University of Otago, 1972; 'The Medico-Social Aspects of Diabetes Mellitus', Preventive Medicine Dissertation, University of Otago, 1973. The University of Otago Library requests anonymous citation of dissertations in this collection.

⁹¹ Minutes of the Annual General Meeting of the DANZ, 19 March 1983, p.4, DNZ.

For diabetic societies, self-help included raising awareness that people with diabetes could 'lead full and active lives'.⁹² In 1971, the DANZ had an unprecedented opportunity for such awareness activities with the World Health Organization (WHO) using its annual World Health Day to commemorate the fiftieth anniversary of the discovery of insulin. Adopting the theme 'A full life despite diabetes', this was a time to celebrate the therapeutic advances of the past half century, but also was accompanied by an international awareness campaign to remove discrimination from the lives of people with diabetes.⁹³ In New Zealand, the Health Department issued press releases and circulated publicity materials from the WHO.⁹⁴ The DANZ's medical advisors wrote articles for the Department's public educational magazine, *Health*, and the nursing journal, *Kai Tiaki*. At the local level, the Health Department's District Health Offices jointly organised campaigns with diabetic societies, although the reach of these varied according to individual interest and resources. The Wellington Diabetic Society, at least, reported its campaign resulted in it gaining many new members.⁹⁵ Campaigns generally included newspaper, radio and television coverage, and public displays, usually supported with sponsorship from insulin companies. Campaign material attempted to de-stigmatise diabetes by stressing that 'a diabetic can maintain his place in the community unnoticed' and 'could live a normal life given the proper treatment'.⁹⁶ This message aimed to allay fears, encourage the middle-aged to seek an early diagnosis, and to help young people come to terms with being different from their peers.

Diabetic societies exhibited special concern for the welfare of children with diabetes, and their families, understanding the establishment of camps where children could learn self-

⁹² Department of Health 'Diabetes', Health Information Series Pamphlet No.211, Wellington, 1971.

⁹³ 'A full life despite diabetes', *Triangle*, 10, 1, 1971, p.37. World Health Day was April 7, but the campaigns usually ran for a whole week.

⁹⁴ Memorandum to Medical Offices of Health, 9 February 1971, International Health – WHO – World Health Day, 1970–73, AAFB 632 W2788 93/ 332/2/14 (39929), ANZW.

⁹⁵ 'World Health Day publicity efforts hit jackpot', *N.Z. Diabetic Review*, 9, 2, June 1971, p.22.

⁹⁶ Department of Health, 'Diabetes'; 'Tests for diabetes offered', *Christchurch Star*, 3 April 1971.

responsibility as one of their primary tasks. In the interwar period, children's health camps flourished throughout the Western world as part of efforts to foster healthy young citizens, amidst anxieties about national efficiency.⁹⁷ Camps for children with diabetes also had a more direct impetus; the first was held in 1925 in the United States, just three years after the discovery of insulin. Pioneering diabetes doctors and researchers, including Elliot P. Joslin and Charles Best, were involved in setting up camps in America and Canada by the 1940s.⁹⁸ The BDA held three camps before the outbreak of the Second World War.⁹⁹ The first camp in Australia was in Sydney in January 1938; individual hospitals and state diabetic associations regularly sponsored subsequent events.¹⁰⁰ These camps aimed to provide children with the necessary instruction and confidence to manage their lives – which would be dictated by a regimen of dietary restrictions, urine (and later blood) testing, and insulin injections – in a fun and relaxed environment. The latter was important because, as one of the DANZ's medical advisors noted, the child with diabetes tended to be 'a bit over-mothered'.¹⁰¹ Having a child with diabetes was hard for parents, who faced challenges like distinguishing insulin reactions from the normal behaviour of childhood and adolescence; many would have welcomed camps for their own respite.¹⁰²

New Zealand diabetic societies began holding children's camps in the late 1960s. In 1964, the Auckland Society's Secretary, John Nesfield, travelled to the United States, where he visited camps in San Francisco and Boston and interviewed their managers about their organisation,

⁹⁷ Margaret Tennant, *Children's Health, The Nation's Wealth; A History of Children's Health Camps*, Wellington, 1994; Margaret Tennant, 'Children's health camps in New Zealand: the making of a movement, 1919–40', *Social History of Medicine*, 9, 1, 1996, pp.69–87.

⁹⁸ G.R. Maslow and D. Lobato, 'Diabetes summer camps: history, safety and outcomes', *Pediatric Diabetes*, 10, 4, 2009, p.278.

⁹⁹ Jackson, p.19.

¹⁰⁰ Martin, p.124.

¹⁰¹ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.26, DNZ.

¹⁰² Jackson, p.19.

supervision and activities.¹⁰³ Nesfield did not have diabetes himself but was a strong advocate of camps because his wife, Joan, had suffered terribly in her youth from uncontrolled diabetes; he believed that if such facilities had been available to her, Joan could have avoided much suffering.¹⁰⁴ As he told the DANZ's 1965 annual meeting, camps taught children 'how to live as a controlled diabetic ... it makes them self-reliant'.¹⁰⁵ Auckland thus directed most of its resources into finding a permanent campsite. In 1968, it obtained quarter share ownership of a site at the new Totara Park development in South Auckland for \$5000 with the area's local authority, the Manukau City Council, subsidised \$20,000 of the development.¹⁰⁶ Auckland ran annual camps there from 1969, with John and Joan Nesfield serving as 'camp father' and 'camp mother' for many years. The Christchurch Society organised the DANZ's first national camp at Wainui in August 1968, and following this the DANZ endeavoured to hold a national camp, organised by a different local society, every year.¹⁰⁷

The efforts to staff and fund these camps reveal some of the interactions between voluntary and government welfare. Local societies were responsible for fundraising for camps in their area, which in the early 1970s meant some camps could not go ahead. Most camps had to charge parents a minimal fee. Although the Health Department officially stated its support of the camps, and its Medical Officers of Health distributed camper applications, local societies had to arrange medical, nursing and dietetic support through their own local hospital board.¹⁰⁸ The Board's support was not always straightforward as the Auckland Society's difficulties in 1975 and 1976 demonstrate. Auckland's 1975 camp had a restricted programme because the

¹⁰³ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.26, DNZ.

¹⁰⁴ Durling, p.14. Eventually Nesfield set up a trust in memoriam to his wife to help less affluent children attend camps: see Dawson, p.77.

¹⁰⁵ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.267, DNZ.

¹⁰⁶ Minutes of the Annual General Meeting of the DANZ, 14 June 1969, p.4, DNZ.

¹⁰⁷ *ibid.*

¹⁰⁸ Director of Public Health to Secretary of DANZ, 29 June 1976, Diseases – Diabetes, 1975–80, ABQU 632 W4415 267/ 131/20 (52881), ANZW; Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

Society could not obtain a resident doctor or dietitian and had lay personnel supervising injections and testing. Nesfield approached the AHB to second staff for 1976.¹⁰⁹ The AHB responded that this request was ‘quite outside the board’s powers and responsibilities’, and permitted staff participation only on a voluntary basis.¹¹⁰ A miscommunication led an Auckland Hospital dietitian to believe the Board would pay for her service at the 1976 camp and the AHB reluctantly did so. The Hospital’s Deputy Medical Superintendent questioned whether in the future ‘a presumably important activity such as this annual camp should depend on the finding of volunteers’?¹¹¹ Citing financial constraints, the Board’s policy remained that any personnel’s involvement with such camps was on their own time.¹¹² This experience supports Margaret Tennant’s finding in relation to the children’s health camp movement in New Zealand: there were ‘permeable boundaries between state employment and voluntary work’.¹¹³

Other government agencies, the charitable and the commercial sectors were more forthcoming in financial support for the diabetes camps. The insulin maker, Novo, provided regular grants from 1976 for both the national and Auckland camps and in 1979 the Ministry of Recreation and Sport, the Child Health Research Foundation, and Handicapped Children’s Foundation all pledged substantial ongoing assistance for the national camps.¹¹⁴ By the early 1980s, the camps were one of the DANZ’s most successful activities.

¹⁰⁹ Nesfield to Dr Frank Rutter, 20 August 1975, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

¹¹⁰ Chief Executive AHB to Nesfield, 18 September 1975, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

¹¹¹ Deputy Medical Superintendent Auckland Hospital to Chief Executive AHB, 9 February 1976, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

¹¹² Chief Executive AHB to Medical Superintendent Auckland Hospital, 5 April 1976, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

¹¹³ Tennant, *The Fabric of Welfare*, p.95.

¹¹⁴ Annual Report of the DANZ for the Year Ended 31 December 1979, p.2, DNZ.

Fundraising for research to cure, or prevent, diabetes was another activity that diabetic societies viewed as an expression of self-help. Around the world, supporting research was a major objective of most societies, whose founders and members hoped that scientists might find another medical miracle like insulin.¹¹⁵ New Zealand was no different. The Nelson Society President Mr L.H. Beardsley wrote in his society's newsletter in the late 1950s, 'If you are content with your diabetes, the answer is simple, do nothing about it, and you will have it for the rest of your days, and some of your children too, will inherit it as a result. The decision is yours.' Alternatively, the responsible person with diabetes would realise, 'Your very life today, is due to research and those two great Canadian doctors, the late Sir Frederick Banting and his surviving partner Professor Charles Best CBE, for these men discovered insulin... Give [Best] the tools and he will finish the job.' In its first few years of existence, the Nelson Society sent hundreds of pounds directly to Best.¹¹⁶ In 1964, the DANZ established a National Research Fund to support a New Zealand research fellow who, as John Nesfield enthused, might become the next Banting or Best: 'a young scientist in New Zealand may ... give the key to the prevention of the onset of this incurable disease'.¹¹⁷ He contended that promoting research was the greatest thing the Association could do to encourage public support.

In fundraising for research, the DANZ's strategy was to underscore that people with diabetes were not simply asking for charity. John Reid suggested to the 1963 annual meeting that 'every effort should be made to produce as much money ourselves' before approaching other funding agencies, and delegates agreed 'that the Association should not have the appearance

¹¹⁵ The IDF Mission was (and is) to advance diabetes care, prevention and a cure worldwide. The Diabetes Federation of Australia, however, did not fundraise for research until 1976 as its 'focus was entirely towards improving the facilities and care of the diabetic on the street': see Martin, p.54.

¹¹⁶ Jamieson, pp.6-7.

¹¹⁷ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.11, DNZ.

of another charitable organisation'.¹¹⁸ The DANZ held several national raffles and individual societies donated various amounts from local fundraising and subscriptions. For instance, the Christchurch Society distributed a brochure to over 5000 businesses and individuals which emphasised its key points via bold typeface: **'Diabetics, by their own initiative, have already raised approximately £3000'** and, **'In the eight years since the Christchurch Society was formed this is the first occasion that we have made a direct appeal for assistance.'**¹¹⁹ According to the Christchurch Medical Officer of Health Lesley Frank Jepson, 'the Public Health Service fully support[ed] the aims and objects of the appeal'.¹²⁰ As in voluntary welfare arrangements, there was an increasingly ad hoc approach to medical research funding in the 1960s. Non-governmental organisations, like the DANZ, often operated on the (correct) assumption that state agencies, such as the Medical Research Council (MRC) or Golden Kiwi Distribution Committee, would sustain projects it started.¹²¹ In 1969, the DANZ awarded its first fellowship to Dr Christopher Lovell-Smith to work under Otago University's Biochemistry Professor J.T. Sneyd on MRC and Golden Kiwi-funded studies of metabolism in diabetes and obesity.

Following the establishment of societies overseas, and becoming part of an international organisational network, societies of people with diabetes emerged in New Zealand at a time of consensus about the value of the welfare state. While their executives wanted more state support for people with diabetes, they claimed not to be 'bludgers' on the public purse and even shared resources with the Health Department, for example, in public awareness

¹¹⁸ Minutes of the Annual General Meeting of the DANZ, 22 June 1963, p.4 DNZ.

¹¹⁹ 'National Research Fund: Christchurch acts', *N.Z. Diabetic Review*, 4, 2, November 1965, p.11.

¹²⁰ *Ibid.*

¹²¹ J.A Borrows, 'Report of the Conference of Medical Research Funding Organizations', 25 September 1972, p.1; Dr J.V. Hodge, 'Conference of Research Funding Organisations, 1 September 1972: Introduction', Golden Kiwi Medical Research Distribution Committee 1970–72, AAFB W4914 632 Box 86 240/53 1 (46949), ANZW.

campaigns.¹²² They saw themselves epitomising self-help, and they promoted this strategy in the belief that this empowered individuals with diabetes to deal with the ‘little interest’ shown ‘by outsiders’.¹²³ Nevertheless, raising funds inevitably drew in outsiders – governmental and other non-governmental agencies – as did the need to work with health professionals.

They ‘didn’t want people with diabetes talking to each’: lay-professional relationships

In a 2001 interview, Professor Donald Beaven recalled one afternoon in 1955 when Maitland Sheppard came to visit him at the Christchurch Diabetes Clinic. Sheppard had come to request his help with setting up a diabetic society, following a rebuff elsewhere. The NZBMA had said they ‘didn’t want people with diabetes talking to each other because they’d all get the wind up about going blind’.¹²⁴ Beaven, who identified himself as a ‘stirrer’ and ‘socialist sympathiser’, believed the NZBMA was a politically conservative establishment, which felt threatened by lay groups that might challenge the power hierarchy between doctors and patients.¹²⁵ However, examining the interactions and motivations between medical professionals and lay people involved in diabetes associations in New Zealand presents a more complex view of their power relations.

Diabetic societies considered that their public acceptability and their ability to promote self-help were contingent upon support from the medical profession. On its formation, in 1934, the BDA established a Medical Advisory Committee of forty physicians from across Britain, and medical professionals made up a high proportion of the BDA’s Executive Committee. The IDF also aimed to advance diabetes care through linkages between the medical, scientific and

¹²² Reid, ‘Using public relations to help’, p.3.

¹²³ ‘Diabetics neglected’.

¹²⁴ Professor Don Beaven, Interviewed by Bee Dawson, 14 May 2002, Transcript OHA-6125, Diabetes New Zealand History (OHColl-0786), Alexander Turnbull Library, Wellington (ATL).

¹²⁵ Mike Crean, ‘Sir Donald Ward Beaven, 31 August 1924 – 4 November 2009’, NZMJ, 122, 1307, 11 December 2009, pp.129–32.

patient communities. After Sheppard's rejection by the NZBMA, he approached Beaven and his colleague Horatio Donald, who became medical advisors to the Christchurch Diabetic Society.¹²⁶ Sheppard told the *Christchurch Star Sun* in 1958 that, as in Australia and Britain, the society was 'similarly backed by a large number of doctors – ninety-four in Christchurch alone'.¹²⁷ In Auckland, John Luxford had written to local doctors regarding a proposed society and requested their 'willingness to co-operate, and agreeing to become an associate member' while emphasising that 'world famous' doctors R.D. Lawrence and Elliot Joslin were leading the international movement.¹²⁸ In a circular to people with diabetes, he noted 'already we have been promised support by several leading doctors'.¹²⁹ Laypeople spearheading the diabetic society movement felt people with diabetes had benefitted greatly from scientific medicine and wanted this to continue. More generally, as Linda Bryder has argued in relation to other health consumer groups emerging at this time, they 'saw allying themselves with doctors as a route to public respectability, which speaks to the status of medicine in the mid-twentieth century' and public attitudes towards it.¹³⁰

Physicians developing diabetes medicine in New Zealand also saw benefits in an alliance with lay organisations in providing access to research funding and international exchange. After two years in the United States studying diabetes on a Fulbright Scholarship, Beaven returned to Christchurch to take up the role of Director of the new Medical Unit at Princess Margaret Hospital, where he proposed to develop a research programme in endocrine and metabolic

¹²⁶ Ibid.

¹²⁷ 'Diabetics neglected'.

¹²⁸ J.H. Luxford, template of letter to doctors, 13 June 1958, ZABV 4638 A1073 198/a 95/1/44 part 1, ANZA.

¹²⁹ Luxford, 'Important notice to diabetics'.

¹³⁰ Bryder made this comment in relation to the New Zealand Federation of Parents' Centres: Linda Bryder, *The Rise and Fall of National Women's Hospital: A History*, Auckland, 2014, p.80. Plunket also used this strategy: see Bryder, *A Voice for Mothers*, p.110.

studies.¹³¹ Meanwhile Dr Jack Kilpatrick, a more senior physician and university academic at Dunedin Hospital, was introducing innovative aspects of multidisciplinary practice into the diabetes clinic there in the early 1960s.¹³² Both doctors were advisors to their local diabetic societies and, with the formation of the DANZ in 1962, believed it too should have a medical advisory committee. They encouraged the National Secretary, John Reid, to pursue this with the NZBMA.¹³³ The NZBMA rejected the idea, but offered to help societies where possible and when asked, so Reid reported ‘that better liaison could best be established by getting the present interested doctors to spread their interest further’.¹³⁴ The DANZ had approached Beaven, Kilpatrick and Auckland endocrinologist Dr Kaye Ibbertson in 1963 about potential research projects needing funding. In January 1964 Kilpatrick wrote to Beaven regarding research needs and asked, ‘Should we form a medical section or an advisory panel to make use of federation with the IDF?’¹³⁵ They decided to initiate further discussion with other doctors interested in diabetes at the Royal Australasian College of Physicians meeting in October. At that meeting, they suggested that physicians who joined the DANZ would benefit from the ability ‘to contact physicians overseas interested in diabetes and attend Diabetic Federation conferences etc’.¹³⁶ The twenty physicians in attendance recommended forming ‘an Advisory Committee to the Association, if the Association wanted it’ and elected Kilpatrick as Chair, Beaven as Honorary-Secretary, and Drs Dennis Hanna of Auckland and Malcolm Watt of Wellington as members. In December 1964, the DANZ accepted the Panel, with Watt to represent it at meetings of the Executive.¹³⁷

¹³¹ D.W. Beaven, ‘Tour report: being a report on observations made during a tour around certain hospitals and medical centres in North America, Europe and Australia, 1958–59’, D.W. Beaven Papers, Accession #195 36817, MBL.

¹³² J.D. Hunter, ‘Kilpatrick, John Alexander’, n.d., URL: <http://www.racp.org.nz/page/library/college-roll/college-roll-detail&id=908>, accessed 26 May 2014.

¹³³ Don Beaven, ‘Medical Panel to advise “Lay” Society’, *Diabetes*, Autumn 2009, p.33.

¹³⁴ Minutes of the Annual General Meeting of the DANZ, 22 June 1963, p.4, DNZ.

¹³⁵ Kilpatrick to Beaven, 26 June 1964, D.W. Beaven Papers, Accession #195, 36775, MBL.

¹³⁶ Minutes of a Meeting of Physicians Interested in Diabetes at Wairakei at the time of the College of Physicians conference, 2 October 1964, ZABV 4638 A1073 198/a 95/1/44 part 1, ANZA.

¹³⁷ Minutes of a Meeting of the Executive of the DANZ, 7 December 1964, DNZ.

In the 1960s, the Medical Panel and lay organisation had a mostly co-operative relationship. The Panel corresponded regularly and met informally a couple of times during the year. On the night before the DANZ's annual meetings, the Panel met to discuss what they would report the next day. Their discussions mainly dealt with co-ordinating medical services in the hospitals, liaison with the Health Department, and educational resources. They also discussed how to spend the DANZ's research fund and fund visits of eminent specialists to New Zealand. The Panel, however, would also report on any issues that societies requested and were proactive about cases of discrimination. Reid expressed appreciation in the DANZ's 1968 annual report for the Panel's 'continued sound advice on many matters' but that there was 'one cloud' in 'the continued pressing of some associations for action to get "special diabetic" foods available'.¹³⁸ Some societies, including that of Nelson, had been effectively founded on the desire of members to lobby for the removal of tariffs on and increased imports of diabetic chocolate. The Panel had to restate its position that people with diabetes should 'find balance within normal foods' and avoid "special" foods which may not contain sugar but still had high carbohydrate or calorific values.¹³⁹ While Reid thought this discussion was a waste of the Panel's time, other members thought the Panel could be more sensitive to the hardship of children who could not enjoy treats like their friends without diabetes.¹⁴⁰

From 1969, the Panel included a member from the Health Department, which changed the nature of the DANZ's interactions with government. As discussed previously, there was a long history of lay societies approaching the Department or Minister of Health to lobby, or for official approval of their activities. In 1965, the DANZ requested that the Panel seek official recognition as an advisory committee on diabetes to the Department. While the Department

¹³⁸ Annual Report of the DANZ for the Year Ending 31 March 1968, p.2, DNZ.

¹³⁹ Ibid.

¹⁴⁰ Minutes of the Annual General Meeting of the DANZ, 8 June 1968, p.7, DNZ.

rejected this request, it did seek advice from the Panel on diabetes issues.¹⁴¹ These interactions, particularly in the area of early detection and educational public health campaigns, reached a point where both the Department and Panel saw it necessary for a more formal channel of co-operation and the Division of Public Health's Dr Bryan Christmas joined the Panel.¹⁴² This new relationship served to mediate lay access to the Department through its medical advisors.

The DANZ's Medical Panel played an important role in influencing Health Department policy on diabetes, and was part of what Tennant has called the 'increasingly complex field' of voluntary sector and government welfare by the 1970s and 1980s.¹⁴³ Beaven described the Panel in 1982 as 'a quasi government body to which matters are referred by either the diabetes association ... or the Health Department' and which made 'important decisions relating to ... diabetes services throughout New Zealand'.¹⁴⁴ While Beaven perhaps exaggerated the status of the Panel in order to claim travelling expenses from his recalcitrant hospital board, the Panel did have a co-operative relationship with most areas of the Department of Health. Tennant has described such relationships as one of individual and institutional goodwill to meet similar ends, often through dialogue and exchange of resources.¹⁴⁵ Most of the Departmental representatives, at least until the early 1980s, attended meetings regularly and took up matters of concern with areas of the Department outside of their own. Unlike other voluntary organisations, such as Plunket or the Intellectually Handicapped Children's Association, the DANZ did not get significant financial support from the Department, or encounter significant territorial disputes with it over what it perceived to

¹⁴¹ 'File Notes on the Diabetic Association', ABQU 632 W4415 267/ 131/20 (52881), ANZW.

¹⁴² Kilpatrick to Christmas, 6 December 1968; Christmas to Kilpatrick, 20 December 1968 in Diseases – Diabetes, 1965–70, AAFB 632 W2969 35/ 131/20 (44534). For these campaigns, see Chapter Three. The Department maintained a representative on the Panel until 1987.

¹⁴³ Tennant, *The Fabric of Welfare*, p.179.

¹⁴⁴ Beaven to Dr D.R. Hay, 8 February 1982, D.W. Beaven Papers, Accession #195, 36657, MBL.

¹⁴⁵ Tennant, *The Fabric of Welfare*, p.190.

be lay encroachment in medical fields.¹⁴⁶ This was likely due to the division of lay and medical responsibility within the DANZ.

In the 1970s, however, lay members challenged the Panel on this division in a dispute over research funding. In 1972, on the recommendation of the Panel, the DANZ granted three years funding to a young Auckland doctor, Stuart Ross, to undertake research in Montreal on the hormones involved in insulin secretion. Some lay members had concerns that people with diabetes in New Zealand might not benefit from supporting researchers working overseas, but Kilpatrick assured them that the Panel expected Ross would return to New Zealand to take up a position as a clinical physician concentrating on diabetes.¹⁴⁷ Ross, however, did not return, declining an unattractive, hastily put together job in Auckland in favour of a prestigious university appointment in Canada. Bob Smith, a Wellington physician who joined the Panel in 1973 and attended the DANZ's Executive meetings, has recalled that some of the most 'rankling issues' between the Panel and the Executive involved the use of research funds in the wake of Ross's decision; in his view, some members wanted 'blood'.¹⁴⁸ Certainly, in 1975, the DANZ proposed that research it funded 'should concentrate on the sociological aspect of current diabetics which could be primarily the responsibility of lay personnel'.¹⁴⁹ In July 1976, Smith wrote to Beaven that 'the feeling created by Stuart Ross is adverse, and there could be opposition to spending funds on training doctors'.¹⁵⁰ As Beaven wanted to get the Association to fund a year's salary for his protégé, Dr Peter Dunn, to train in America, he felt it necessary to ask Smith to emphasise to the Executive that he was '99.99%' sure Dunn would return to New Zealand.¹⁵¹

¹⁴⁶ *Ibid.*, pp.156–9; 187.

¹⁴⁷ Minutes of the Annual General Meeting of the DANZ, 8 April 1972, p.1, DNZ.

¹⁴⁸ Dr Bob Smith, Personal Communication, 3 June 2011.

¹⁴⁹ Minutes of the Annual General Meeting of the DANZ, 8 March 1975, p.6, DNZ.

¹⁵⁰ Smith to Beaven, 8 July 1976, D.W. Beaven Papers, Accession #195, 36788, MBL.

¹⁵¹ Beaven to Smith, 6 August 1976, D.W. Beaven Papers, Accession #195, 36788, MBL.

These tensions in lay-medical relations within the organisation could reflect the broader consumerist challenge to medical authority at this time. The self-help movement in Western health care expanded significantly from the 1970s as more patients questioned the benefits of modern medicine and the accountability of medical professionals. An intellectual movement, led by academics such as philosopher Ivan Illich and University of Birmingham Professor of Social Medicine Thomas McKeown, argued against the dominance and success of high tech medicine. The feminist movement added fuel to such critiques by denouncing doctors for their patriarchal control over women's bodies. Smith recalled that there was 'in the community a feeling that doctors and others needed to be kept in their place', and that some doctors 'retreated from involvement with patient organisations because of the rise of consumerism'.¹⁵² He also remembered how in the late 1970s the Medical Panel wanted to transfer its advisory function to the DANZ to a new organisation of professionals, the New Zealand Society for the Study of Diabetes, but the DANZ resisted, as it did not want to lose control of the relationship.¹⁵³

In other respects, the co-operative relationship persisted between the Panel and lay administration. The DANZ Secretary in the 1970s, George Vincent, agreed with Beaven that 'it does no harm to maintain good public relations with the medical profession', and despite the difficulties with the Stuart Ross debacle, the DANZ continued to endorse the Panel's recommendations on research funding applications.¹⁵⁴ By the end of the decade, the DANZ had provided fellowships to Dr Peter Dunn, Dr Russell Scott and Dr John Baker, who all became leading diabetes specialists in New Zealand in the 1980s. Moreover, in 1980, the DANZ moved on the Panel's request to change its research fund to a National Research and

¹⁵² Dr Bob Smith, Personal Communication, 3 June 2011.

¹⁵³ Ibid. For the formation of the New Zealand Society for the Study of Diabetes, see Chapter Four.

¹⁵⁴ Beaven to Vincent, 15 June 1974, Vincent to Beaven, 5 August 1974, D.W. Beaven Papers, Accession #195, 36788, MBL.

Education Fund, which expanded the fund's purview to supporting medical professionals and allied health professionals who wished to attend conferences or undergo further training.¹⁵⁵

One past President has reflected that some lay members felt the Panel did not always fight hard for the things the DANZ wanted subsidised by the government.¹⁵⁶ While most of the Panel members believed people with diabetes needed more government support, as doctors working closely with health officials who were trying to prioritise scarce resources, they could be cautious to ensure the value of new technologies before recommending them and were realistic about what they could get from government.¹⁵⁷

The growth of diabetic societies in New Zealand came at a time of significant change in the relationship between medical professionals and lay people – from one where doctors held cultural authority to one of increased public questioning of that authority. Beaven believed that, by not supporting the DANZ, a politically-conservative, organised medical profession in New Zealand were showing themselves up as scared of these changes. The diabetic societies, however, were based on an older model of co-operation between doctors and lay people in their joint interests of advancing the welfare of people with diabetes and scientific understanding. The DANZ's lay leadership characteristically adhered to its Medical Advisory Panel's advice and priorities, but the relationship could also be contentious. On the other hand, the DANZ's co-operative relationship with the Health Department, to the extent a departmental representative sat on the Medical Panel, limited lay members' scope to increase welfare demands outside of professionals' recommendations and reduced its role as a pressure group.

¹⁵⁵ Minutes of the Annual General Meeting of the DANZ, 8 March 1980, p.4, DNZ.

¹⁵⁶ Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

¹⁵⁷ For instance, Smith was against making disposable syringes free as it 'would be a wasteful and inappropriate use of scarce resources for health care': Minutes of a Meeting of the Medical Advisory Panel, 12 March 1976, DNZ. Beaven told DANZ that they should focus lobbying on non-disposable syringes, as they were more likely to be successful: Minutes of the Annual General Meeting of the DANZ, 19 March 1977, p.3, DNZ.

Conclusion

In 1977, the Deputy Director-General of Health, Dr Ronald (Ron) Barker, opened the annual conference of the DANZ with a speech traversing the history of voluntary service in the health field. Barker relayed that one of the more useful functions of voluntary organisations was ‘in removing a sense of stigma which had historically attached to some diseases’ and stated ‘that the bringing in of a comprehensive health service or social security scheme has not removed the need for voluntary services’.¹⁵⁸ He went on to describe how the state, medical profession and voluntary sector could work together: voluntary organisations could identify ‘deficiencies in the system’ to be fixed, while ‘the association of people with a similar disease gives them strength and the capacity to cope’. Advances in medicine were now also stimulating ‘membership of societies and ... a strong motivation for self-help’. In providing a ‘consumer point of view’, organisations like the DANZ could help the medical profession and government in ‘the methods of dealing with cases’.¹⁵⁹ Reflecting the trend towards patient empowerment emerging at the time, Barker implied organisations of people with diabetes had an important role to play, as the consensus over the ultimate responsibility of the state for welfare services was becoming less certain.

Historical scholarship on diabetes associations, which has tended to focus on the interests of physicians and their educational objectives, has underemphasised that the early concerns of these organisations related to the social welfare of people with diabetes following the advent of insulin treatment. This chapter has demonstrated the importance of these concerns and emphasised the ways New Zealand’s history of the welfare state influenced local expressions of international trends. New Zealand first formed an organisation, the NZDWA, with explicit welfare objectives in the context of the Second World War. The NZDWA provided a voice to

¹⁵⁸ Minutes of the Annual General Meeting of the DANZ, 19 March 1977, p.1, DANZ.

¹⁵⁹ Ibid.

people with diabetes who were worried about government preparedness to meet their health needs during the war, engaging in both lobbying and active self-help. After this crisis subsided, a movement of societies of people with diabetes developed under a national umbrella organisation, the DANZ, from the 1960s. That organisation continues today. As voluntary responses to the social problems of people with diabetes, the organisations emerged and grew in complementary ways to the welfare state, out of a sense of civic responsibility. While the lay leadership lobbied for greater government support and challenged its medical advisors at times, the diabetic societies practiced a conservative brand of self-help. Their key emphasis was on people with diabetes taking responsibility for their own health and welfare through social support, voluntary contribution and following medical advice. In doing this, these organisations were acting strategically: demonstrating that people with diabetes could live a normal life as productive citizens helped challenge the stigma associated with diabetes and, as the next chapter will discuss, gave diabetic societies legitimacy in initiating public health campaigns for early detection.

CHAPTER THREE

‘The question of undiagnosed diabetics should be of concern to the whole community’: diabetes detection campaigns, 1960s to 1980s

In June 1966 the Minister of Health, Don McKay, opened the annual general meeting of the Diabetic Association of New Zealand (DANZ) with an address in which he called ‘the work of the association most valuable, not only to its members but also to the community’ as ‘the question of undiagnosed diabetics should be of concern to the whole community’.¹ He informed those in attendance that, ‘as and when staff are available the Health Department will pursue detection campaigns’. Since its formation in 1962, the DANZ had seen its duty as not only promoting the welfare of people with diabetes; uncovering those in the community who did not yet know they had the disorder was one of its founding objectives.² McKay’s appearance at the DANZ meeting, and his guarded commitment of staff to detection campaigns, suggests the government also saw ‘hidden diabetes’ as a public health concern.

Across the Western world after the Second World War, health officials, medical professionals, pharmaceutical companies and voluntary organisations began mass detection of asymptomatic, undiagnosed people with diabetes in the community. While sometimes having epidemiological objectives, detection surveys were also considered public health campaigns which emphasised that diabetes was often hidden, but if found early could be easily managed and its negative effects avoided.³ New Zealand began such campaigns in the early 1960s yet,

¹ Minutes of the Annual General Meeting of the DANZ, 11 June 1966, p.1, Diabetes New Zealand, Wellington (DNZ).

² The DANZ Report of the Executive Committee for the Period Ended 31 March 1963, p.3, DNZ.

³ Pharmaceutical companies had vested commercial interests in the drive to find more people with mild diabetes who could take their new oral hypoglycaemic drugs in the 1950s and 1960s. In the American context Jeremy Greene has connected the expansion of screening for asymptomatic diabetes and ‘prediabetes’ to the marketing of drug manufacturers: Jeremy A. Greene, *Prescribing by Numbers: Drugs and the Definition of Disease*, Baltimore, 2007, pp.83–112.

by the 1970s, the apparent consensus around detection drives was disintegrating and there would be no national screening programme for diabetes, as proponents had envisaged.

This chapter examines the reasons behind the rise and decline of diabetes detection campaigns in New Zealand and the debates between lay people, medical professionals and health officials over the responsibility for, and direction of, this public health strategy. Recent histories dealing with disease screening have highlighted the ‘tremendous enthusiasm for the powers of modern technology’, the ‘capital organisational and symbolic investments’, ‘single-issue health advocacy’ and political drivers involved in shaping programmes in New Zealand.⁴ In line with these historians, in this chapter I will argue that the shifting fate of diabetes detection campaigns was driven not by any clear evidence of their usefulness or efficacy, but rather by factors such as technological developments, international directives and interest group advocacy.

‘Hitherto unknown diabetes’: the Health Department’s diabetes surveys

Following the United States Public Health Service’s 1946–47 diabetes survey in Oxford Massachusetts, which found three previously undiagnosed cases for every four known people with diabetes, the Western world became gripped with the idea that it could, and should, detect all ‘hidden diabetics’.⁵ The development of self-administered urine testing strips in the 1950s, and optimism about the new oral hypoglycaemic treatment in the late 1950s, made mass detection much more feasible and attractive to doctors, health authorities and a public

⁴ Linda Bryder, *A History of the ‘Unfortunate Experiment’ at National Women’s Hospital*, Auckland, 2009, p.15; Deborah Ann Dunsford, ‘Seeking the Prize of Eradication: A Social History of Tuberculosis in New Zealand from World War Two to the 1970s’, PhD thesis, University of Auckland, 2008, p.99; Deborah Mary Jowitt, ‘Government Policy Relating to Hepatitis B in New Zealand 1970–2005’, PhD thesis, University of Auckland, 2010, pp.30, 213–56.

⁵ See Chapter One and Aaron Pascal Mauck, ‘Managing Care: The History of Diabetes Management in Twentieth Century America’, PhD dissertation, Harvard University, 2010, pp.209–13. For a summary of detection drives conducted between 1945 and 1964, see World Health Organization, *Diabetes Mellitus: Report of an Expert Committee*, Technical Report Series No.310, Geneva, 1965, Annexe 1, pp.39–40.

enthused by the potential of modern medical science to catch and treat disease before it was visible.⁶ Learning from their overseas counterparts, in the early 1960s individual medical officers of health in New Zealand began screening surveys ‘to detect the incidence of hitherto unknown diabetes in the community’.⁷

In May 1963, after reading several articles about the subject in public health journals, the Medical Officer of Health for Palmerston North, N.T. Barnett, put forward a proposal to the Director-General of Health, Harold Turbott, to conduct a diabetes detection survey in the small town of Otaki, on the North Island’s west coast.⁸ Barnett proposed to follow the methodology of a British Medical Officer, J. Dewar, who had organised diabetes tests to accompany the mobile x-ray unit for tuberculosis screening of burgh and small county areas in 1962. For Dewar’s survey, visitors to the x-ray unit received urine test strips, Clinistix, with instructions on how to use them and report back the results. The participant’s family doctor then followed up positive test results and made the diagnosis of diabetes.⁹

Barnett suggested Otaki was a good place for a similar survey in New Zealand because of its concentrated population of 2,900, which included a proportion of Maori.¹⁰ The Department’s 1960 report, *Maori-European Standards of Health*, had revealed that Maori had a much higher mortality from diabetes than Pakeha and attributed this to their failure to seek medical advice at an early stage.¹¹ The mobile x-ray unit was also due to visit the area. Mass x-ray screening for tuberculosis was the most extensive and long-running public health campaign of

⁶ For a discussion of similar developments in relation to cervical cancer, see Bryder, pp.7–15.

⁷ N.T. Barnett, ‘Diabetes detection survey’, *New Zealand Medical Journal* (NZMJ), 63, May 1964, p.309.

⁸ Barnett to Turbott, 22 May 1963, Diseases –Diabetic Survey, 1920–71, ADBZ 16163 H1 1237/ 131/20/6 (45365), Archives New Zealand, Wellington (ANZW).

⁹ Barnett, p.309.

¹⁰ It also had a small number of Chinese residents but Barnett did not separate them out in his analysis.

¹¹ R.J. Rose, *Maori-European Standards of Health*, Department of Health Special Report No.1, Wellington, 1960, p.29. For a detailed discussion of this, see Chapter One.

the post-war years in New Zealand; by attaching a diabetes detection tent to the operation, a clear message would be sent to the community that diabetes was now also an important public health issue.¹² The association with tuberculosis screening also reinforced a message that early detection could allow more effective therapy. As far as Barnett was aware, this would be the first survey of its kind in New Zealand. He believed that the overseas surveys, and New Zealand's mortality and morbidity figures for diabetes, demonstrated the need for his proposed survey.¹³

Detecting hidden diabetes evoked competition between medical officers of health as they vied to be the first to undertake this new public health initiative in New Zealand. S.H. Moore, Medical Officer of Health for Invercargill, wanted to survey his district over 1963–64 after reading in *Medical News* about Medical Officer, Dr Samuel Hayes' investigation in Birmingham, England, which reportedly found an incidence of 7 per cent previously undiagnosed. Moore wrote to Hayes for further details on the scheme before asking the Director-General of Health in August 1963, presumably unaware of Barnett's proposal, for permission to proceed in Invercargill. He justified his proposed survey by pointing out both its epidemiological value and the 'distinct benefit in ensuring that a number of early cases of the disease get treatment in good time'.¹⁴ Turbott informed Moore of Barnett's survey and told him to contact him for advice.¹⁵ Moore did follow up with Barnett, but it appears he was somewhat aggrieved at not being able to claim his survey as the first of its kind in New Zealand. A newspaper article for the publicity campaign reported under the sub-heading 'Own

¹² Dunsford, pp.99–149.

¹³ Barnett, p.309. The Wellington Medical Unit's health survey of the Maori community of Ruatahuna in January 1962, however, included diabetes detection; for details of this survey, see Chapter One.

¹⁴ Moore to Turbott, 5 August 1963, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

¹⁵ Turbott to Moore, 12 August 1963, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

Idea' that Moore's 'survey was his own idea ... and had only been started in one other centre in New Zealand ... he had got the idea from an English medical publication'.¹⁶

Extensive publicity campaigns and community input were a prerequisite for diabetes surveys. Barnett met with groups such as the Country Women's Institute, Jaycees, Plunket, Parent Teacher Associations and Maori Tribal Committees to enlist their help in spreading the word about the survey.¹⁷ He also consulted with local general practitioners to ensure they could follow up people with positive test results. The doctors were enthusiastic: some even spoke at public meetings during the publicity campaign. Barnett believed their efforts were 'most helpful as it seems that patients are generally more likely to co-operate in such a venture if their doctor thinks it is a good thing'.¹⁸ Although Barnett was unable to organise radio publicity, he made good use of community talks, posters and newspaper articles. So much so, that people in the adjacent township of Te Horo requested, successfully, to participate.¹⁹

Survey publicity stressed the perceived benefits to participants and avoided anything that might cause, in Barnett's words, 'undue apprehension'.²⁰ Newspaper reports informed Otaki residents over fifteen years of age they were 'the pilot group of the Dominion' to do the simple self-administered test for their health.²¹ As this capitalised statement suggests, these reports made early detection the dominant message:

IF YOU HAVE GOT DIABETES THE SOONER YOU KNOW ABOUT IT THE BETTER. IT IS SOMETHING THAT CANNOT BE TRIFLED WITH. IF IT IS TAKEN IN HAND EARLY SPECIFIC COMPLICATIONS CAN BE AVOIDED.²²

¹⁶ 'Pilot Diabetes Survey for Bluff', *Southland Times*, 25 October 1963.

¹⁷ Barnett to Turbott, 1 August 1963, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

¹⁸ Barnett, p.309.

¹⁹ *Ibid.*

²⁰ *Ibid.*, p.311.

²¹ Press clipping, "Pilot Group" for Survey, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

²² *Ibid.* Capitalisation in original.

Barnett argued that in designing publicity ‘the main emphasis should be that treatment has advanced to the stage where a sufferer ... can live a normal and useful life provided he is under medical supervision’.²³ He thought highlighting the new blood sugar-lowering tablets would help remove fears about injections, which the public commonly associated with diabetes.²⁴ Barnett believed publicity needed to give people facts about diabetes in such a way that it would not scare them from seeking diagnosis; hence, he did not give details of the ‘specific’ complications.²⁵

Barnett’s survey drew a mediocre response. Participants returned 57 per cent of the 3000 Clinistix strips distributed. Fifty-nine of these strips had a positive result. Family doctors tested the blood sugars of all but two (who refused) of those with positive strips and diagnosed diabetes if these levels reached 120mg per 100ml. The survey found six people with diabetes, all Pakeha and aged between forty and seventy years old. This gave an incidence of diabetes of 0.35 per cent of the returned results.²⁶ While Barnett considered these results both satisfactory and proof of the efficacy of his campaign, the Director of the Division of Health Education, Derek Taylor, felt ‘the response rate ... was not great and one suspects that the preliminary publicity and education was insufficient’.²⁷ Taylor emphasised this to other medical officers of health who wanted to carry out similar screening surveys in their districts.

At the end of 1963 the Medical Officer of Health for Hamilton, J.F. Dawson, proposed a pilot survey for the town of Otorohonga, in the South of his district, to coincide with the mobile x-

²³ Barnett, pp.311–2.

²⁴ This was one of the early marketing strategies for these drugs: see Greene, pp.92–98.

²⁵ *Ibid.*, p.311.

²⁶ *Ibid.*

²⁷ Taylor to Dawson, 31 March 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

ray unit the following year.²⁸ Taylor approved the survey and requested that Dawson inform him of the results in view of the low response rate at Otaki.²⁹ The Otorohonga pilot began in May 1964, but Dawson extended it the following year without reporting to Taylor. The pilot had found that 3.8 per cent of Maori women and 30 per cent of Maori men who returned Clinistix had potentially abnormal urine sugar. Dawson decided this warranted further case detection in the Maori community and in May 1965 he enlisted public health nurses to distribute and collect ten Clinistix per week from ‘at-risk’ groups – those over forty years old, those with a family history of diabetes, and women with large families, particularly if their babies had a heavy birth weight. Within three months private practitioners had confirmed six new cases of diabetes and a further thirteen people had abnormal results that were still under investigation.³⁰

Dawson went on to make a much larger survey over 1967 and 1968 of the entire Maori and Pakeha population in the Hamilton Health District, with the help of the local chapter of the New Zealand Branch of the British Medical Association.³¹ Dawson and the survey’s organising committee believed this joint effort ‘was preferable as the general public seemed far more in favour of schemes run by the medical profession than a Government Department’.³² The survey team sent out Clinistix, instructions and envelopes to general practitioners, chemists, and public health nurses to distribute to patients or inquirers in at-risk groups.³³ If the strip changed colour to a colour that indicated an abnormality, the participants sent it back to Dawson who informed the person’s doctor to organise a follow-up glucose

²⁸ Dawson to Turbott, 19 December 1963, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

²⁹ Taylor to Dawson, 31 March 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

³⁰ Dawson to D.P. Kennedy, Director-General of Health, 3 August 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

³¹ Ibid.

³² ‘Notes on Diabetic Survey Taken at Meeting, Thursday 8 February 1967’, 10 February 1967, Diseases – Diabetes – 1967 Campaign, 1966–69, YCBE 1990 A801 27/b 6/20/4 (6317), Archives New Zealand, Auckland (ANZA).

³³ Dawson to C.L. Scott, 27 April 1967, YCBE 1990 A801 27/b 6/20/4 (6317), ANZA.

tolerance test. Although there were numerous suspect strips returned, there was no statistical analysis of the campaign; it was impossible to calculate the number of instruction forms and testing strips distributed because chemists and doctors did not return the unused ones to the Health Department.³⁴ Moreover, doctors did not consistently forward the results of the glucose tolerance tests, which confirmed a diagnosis of diabetes, to the Hamilton District Health Office, so the survey offered no reliable epidemiological data. Nevertheless, Dawson was satisfied that it had been a justifiable public health measure in the early detection of diabetes.³⁵

The Medical Officer of Health for Whangarei E. Simpson also conducted a pilot diabetes survey in the Bay of Islands in February 1964 to assess the potential for a larger survey of his Health District. The Bay of Islands had a large Maori population whom Simpson found gave a disappointing response rate. Simpson believed Maori needed more targeted publicity. He took advice from a Maori Affairs Officer who suggested a more 'positive' approach; according to one poster aimed at Maori, diabetes was not only treatable, but 'can be easily cured provided it is discovered in its earlier stages'.³⁶ Simpson planned to cover his entire Health District over approximately three years as the x-ray unit moved through. There would be a six-month publicity campaign preceding the survey. At an estimated total cost of £1500, Simpson argued this was 'a cheap price to pay'.³⁷ Although the Bay of Islands pilot had found only one person with diabetes, and Simpson thought his response rate for the entire district would be similar to the Otaki survey, Taylor and Director of Public Health, Dr D.P. Kennedy, agreed and requested a breakdown of his costs.³⁸ In September, Simpson presented his proposal for a

³⁴ J.A.T. Terry to Dawson, 2 September 1968, YCBE 1990 A801 27/b 6/20/4 (6317), ANZA.

³⁵ Dawson to Members of the Survey Planning Committee, 4 September 1968, YCBE 1990 A801 27/b 6/20/4 (6317), ANZA.

³⁶ 'Sugar Diabetes' and Taylor to Simpson, 18 March 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

³⁷ Simpson to Turbott, 13 May 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

³⁸ Ibid.; Taylor to Simpson, 27 May 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

community-wide diabetes screening programme in the Whangarei District.³⁹ Kennedy delayed a funding decision by allowing Simpson to use existing resources to do another survey, in the small northern township of Kamo.⁴⁰

A new technological breakthrough reshaped Simpson's plans for Whangarei. The Ames Company introduced 'Dextrostix' in 1964, which, with only a drop of peripheral blood from a finger prick, would change colour to indicate the level of glucose. Ames marketed the 'instant test for diabetes' as a way to 'simplify the early detection of hidden diabetes'; general practitioners could 'do their own blood sugar laboratory work' and epidemiologists had access to a 'suitcase laboratory'.⁴¹ With the potential of removing the need for a follow-up blood test investigation, Simpson appealed to Taylor that, if he could get these test strips in New Zealand, 'then the whole pattern of a detection survey will be changed and the major source of cost and labour eliminated'.⁴² Indeed, Simpson wanted to conduct a double pilot study testing both urine with Clinistix and blood with Dextrostix.⁴³ There was a delay in the availability and regulatory clearance of Dextrostix in New Zealand but Simpson still held out hope that 'the Department will be able to permit the use of Dextrostix soon whilst public interest is aroused by the Kamo survey'.⁴⁴

Thus, health officials' enthusiasm for detection drives ran high as they read about their overseas counterparts' surveys and new testing materials. In an ad hoc way, individual medical officers of health initiated surveys to uncover how many undiagnosed people with diabetes lived in their districts and to publicise the need for early detection. Publicity

³⁹ Director-General Meeting Minutes, 5 October 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴⁰ Kennedy to Simpson, 8 October 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴¹ 'Instant test for diabetes available soon', extract from *Economic and Industrial News from Britain*, 25 July 1964, in Medical services – Care of diabetics, 1955–1982, ZABV 4638 A1073 198/a 95/1/44 part 1, ANZA.

⁴² Simpson to Taylor, 16 November 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴³ Simpson to Taylor, 15 December 1964, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴⁴ Simpson to Taylor, 4 February 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

campaigns to encourage participation underscored the ease and efficacy of modern treatment, while case finding amongst Maori drew special attention. There was little indication that Departmental officers thought such surveys posed any harm to the community, nor was there much concern about their validity as an efficient use of financial and human resources. The various surveys had mixed results and levels of public support, and it appeared that the involvement of voluntary organisations and the medical profession engendered the best community response.

‘What is the future now for preventive surveys if voluntary bodies ... invade the field’

At the Auckland Easter Show in April 1965, the Auckland Diabetic Society conducted the first detection drive to use Dextrostix in New Zealand. Unaware of how the Society had obtained the Dextrostix, Simpson questioned Taylor, ‘What is the future now for preventive surveys, if voluntary bodies ... are to invade the field?’⁴⁵

The Auckland Diabetic Society was the largest in the country, and its secretary, John Nesfield, was one of the most vocal lay advocates for the interests of people with diabetes, including those who did not yet know they had the disorder. As mentioned in Chapter Two, Nesfield had been a founding member of the Society in 1958, which he joined to support his wife Joan who had diabetes from the age of thirteen. He quickly became involved in all issues concerning the welfare of people with diabetes, which eventually earned him a Queen’s Service Medal and the nickname ‘Mr. Diabetes’.⁴⁶ In 1964, Nesfield attended the International Diabetes Federation (IDF) Congress in Toronto where he witnessed an Ames representative demonstrate how to use the new Dextrostix. On reflection decades later, Nesfield claimed to have seen ‘things one step ahead’ – that Dextrostix could help find

⁴⁵ Simpson to Taylor, 26 April 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴⁶ Marguerite Durling, ‘Diabetes NZ Auckland Inc: celebrating the past, shaping the future’, *Dia-Log*, Spring 2008, pp.2–13.

undiagnosed people in the community.⁴⁷ He brought some Dextrostix from Toronto back to Auckland and arranged with a local Ames representative to supply further product. The Auckland Society set up a caravan at the Easter showground where 659 people took the test.⁴⁸

When Simpson heard about the Auckland Diabetic Society's detection drive he was, in light of his own Dextrostix proposal, incensed and called into question Health Department policy. Writing to Taylor, he vented that the scheme was 'poorly conceived, a blind assessment of blood glucose levels without, so far as I know, any reference to meals, etc'.⁴⁹ The Society had arranged press coverage and television airtime.⁵⁰ Simpson worried that 'the impact on an untrained and uninformed public could well ruin any more orthodox urine test survey', including his Kamo survey, which he believed was now 'compromised'.⁵¹ He asked Taylor why he had not told him that Dextrostix was on the market and questioned the implications for public health authorities if lay people had the right to institute such campaigns.⁵² As already indicated, the Health Department did not have a defined policy for detection surveys and individual medical officers of health had relatively free reign over their conduct. Taylor wrote to Nesfield asking how he had obtained the Dextrostix and for a copy of a report on the survey from the Society's medical advisors. Taylor implied that information from the Society would help him advise interested medical officers on the best survey methods.⁵³ In his reply letter, addressed to Kennedy, who was now Director-General of Health, Nesfield claimed that he had acquired approval from the Health Department's Auckland District Office ahead of the survey. Promising to send the medical report when it was available, Nesfield added, 'It is very

⁴⁷ John Nesfield, Interviewed by Bee Dawson, 6 November 2001, OHInt-0786-09, Diabetes New Zealand History (OHColl-0786), Alexander Turnbull Library, Wellington (ATL).

⁴⁸ Nesfield to Kennedy, 14 May 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁴⁹ Simpson to Taylor, 26 April 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁵⁰ 'Auckland Diabetic Society's Information Centre and Pilot Diabetes Detection Drive Report', Diseases – Diabetes, 1941–65, ADBZ 16163 H1 164/ 131/20 (30435), ANZW.

⁵¹ Simpson to Taylor, 26 April 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁵² Ibid.

⁵³ Taylor to Nesfield, 4 May 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

gratifying to find your Department so interested in this matter which we believe to be in the interests of national health and the economic welfare of the community.’⁵⁴

The Auckland Diabetic Society’s medical review of the detection drive, released at the end of June 1965, outlined the procedure, results and lessons for future detection efforts.⁵⁵ Two technicians from Auckland’s Green Lane Hospital Laboratory had performed the tests. Members of the Society recorded the results of the test as well as the name, address, doctor, sex, and family history of diabetes of each participant. The technicians took the tests in the afternoons and evenings, at a rate of forty per hour, over the two-week show. The public responded eagerly; they had formed long queues and the Society had to turn many away when it ran out of Dextrostix. Seventy-eight people or 10 per cent of those tested had blood sugar levels believed to warrant further investigation, (either over 140mg/100ml or 130mg/100ml for those with a family history of diabetes). The Society referred these people to their own doctor or, if they had not given the name of their doctor, to the Green Lane Hospital Laboratory for a glucose tolerance test. The Laboratory confirmed six of the thirty people it tested had diabetes. The results of the other forty-eight abnormal cases, assumed to have seen their doctors, were not available.⁵⁶

While the report concluded that the pilot had ‘no statistical value and [was] in no way a scientific achievement’, it did support Dextrostix as a suitable method for detection drives.⁵⁷ According to the authors, Dextrostix were practical, acceptable to the public (if brought to them), simple (the technicians needed no special skills), rapid, and, ‘as Accurate [sic] as any other single casual test for blood glucose or urine glucose.’ They suggested that the

⁵⁴ Nesfield to Kennedy, 14 May 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁵⁵ ‘Pilot Detection Drive for Diabetes Using Dextrostix’, 24 June 1965, p.1, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁵⁶ Ibid.

⁵⁷ Ibid., p.2.

Dextrostix's accuracy could be improved if, rather than a casual test taken without reference to the time of last food intake, survey organisers' could find a convenient way for participants to ingest a standardised amount of carbohydrate beforehand.⁵⁸ Nesfield saw the report as persuasive evidence for a national mass screening programme for diabetes and forwarded it to the Health Department hoping it would agree with him.⁵⁹

The Auckland Diabetic Society clearly thought it had a legitimate role to play in detecting people with diabetes, but it expected the government to take a much larger role. A newspaper report on the Easter Show tests evoked the symbolic success of the mobile x-ray campaign in tuberculosis control as a precedent: 'Mass testing for tuberculosis has more than proved its worth; the detection of diabetics is equally important.'⁶⁰ At the DANZ's 1965 annual meeting, Nesfield argued it 'was the responsibility of the Health Department in the interests of national health to bear the cost of any national detection programme'.⁶¹ Medical advisor, Dr Donald Beaven, responded that 'it is up to the Medical Panel [of the DANZ] and those interested in diabetes ... to tell the Department what they should do... The Department has not got anyone more experienced'.⁶² However, he discouraged Nesfield from approaching the Health Department further on a mass screening campaign because he wanted to conduct a more scientific pilot survey than the Auckland Easter Show detection drive. The DANZ decided to leave investigations into a national diabetes detection drive with its Medical Panel.⁶³

Therefore, while the Health Department had no explicit policy to direct its diabetes detection surveys, an opportunistic lay advocate drummed up local medical support and media attention

⁵⁸ Ibid.

⁵⁹ Nesfield to Taylor, 25 June 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁶⁰ 'The diabetic in an affluent society', *Evening Post*, 29 June 1965.

⁶¹ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.25, DNZ.

⁶² Ibid.

⁶³ Ibid., pp.24–25.

to pilot a new testing technology. John Nesfield hoped this would convince the Department to conduct a national screening drive and the Department was not averse to learning from a voluntary organisation's initiative. The Auckland Easter Show detection drive was popular with the public, but did not meet scientific objectives and both the DANZ's Medical Panel and the Department were left with many questions about how next to proceed.

'Absence of information ... should never be accepted as an excuse'

In the mid-1960s, international authorities began assessing the lessons from two decades worth of diabetes detection surveys. A World Health Organization (WHO) expert committee found numerous gaps in the science on glucose tolerance, appropriate diagnostic categories and methods for detecting abnormality. Yet it still argued that, 'Absence of information ... should never be accepted as an excuse to procrastinate about screening programmes.'⁶⁴ In July 1965 these international discussions came to Christchurch.

Held over three days at the Christchurch Hospital, a postgraduate course on diabetes introduced New Zealand doctors and medical officers of health to world-renowned British expert on detection surveys, Professor W.J.H. Butterfield. Butterfield had conducted a large-scale community study in Bedford, England, in 1962, which highlighted a startling prevalence of diabetes and many of the issues around diagnostic criteria and methodology that were arising in epidemiological work internationally.⁶⁵ At the course, Butterfield suggested the current diagnostic blood sugar value in common use – 120mg/100ml – was too low. He believed that 200mg/100ml was truly pathological and that values in between this and the current level constituted borderline cases. Other international experts disagreed; Butterfield had served as Rapporteur for the WHO's Expert Committee on Diabetes Mellitus meeting in

⁶⁴ WHO, *Diabetes Mellitus: Report of an Expert Committee*, p.21.

⁶⁵ W.J.H. Butterfield, 'Diabetes Mellitus', in Thomas McKeown, ed., *Screening in Medical Care: Reviewing the Evidence: A Collection of Essays*, Nuffield Provincial Hospitals Trust, London, 1968, pp.65–80.

Geneva in November 1964 which, he told his audience, had decided to recommend 140mg/100ml as diagnostic of diabetes.⁶⁶

Butterfield's visit provided a timely opportunity for the Health Department to consider the future of diabetes detection surveys in New Zealand. The postgraduate course had one day devoted to several questions the early Health Department and Auckland detection campaigns had generated: how accurate were surveys, what was their value, what standards were used for diagnosis, and what was the role of the medical officer of health?⁶⁷ This inspired a number of medical officers of health to think about detection drives, but Taylor was cautious and requested that they send all proposed surveys to Head Office before committing to them. His memorandum to medical officers stated it was not yet possible 'to decide on any routine procedure for such surveys in New Zealand and it [was] ... important that any surveys conducted be used for making any such decision in the future'.⁶⁸ Not all took this advice, however, as seen in Dawson's continued detection efforts in Hamilton described above.

Soon after Butterfield's appearance in Christchurch the WHO released the Report of its Expert Committee on Diabetes Mellitus which made recommendations for concerted efforts in early detection.⁶⁹ The Report investigated the various forms of population screening for diabetes that had been used over the past two decades. The most common practice, as had been the case in New Zealand, was urine screening followed up with a glucose tolerance test for those found to have glycosuria. The Committee thought this method would be most cost effective, but it could produce many false positives which required more money to be spent in

⁶⁶ 'Notes from Professor Butterfield's Talk at the Post-Graduate Committee Seminar at Christchurch Hospital, 9 July 1965', ADBZ 16163 H1 164/ 131/20 (30435), ANZW.

⁶⁷ Taylor to Nesfield, 21 May 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW; 'Diabetes Mellitus: Nature, Epidemiology and Treatment', Programme, ADBZ 16163 H1 164/ 131/20 (30435), ANZW.

⁶⁸ Taylor to Medical Officers of Health, 16 July 1965, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

⁶⁹ WHO, *Diabetes Mellitus: Report of an Expert Committee*, p.19.

unnecessary follow-ups. It was also problematic in the elderly: Butterfield's Bedford survey had found glycosuria could be absent in many older participants, despite a positive glucose tolerance test, due to their higher renal threshold.⁷⁰ Blood testing, either venous or capillary, was considered more accurate. The Committee encouraged the trend towards blood testing in detection surveys, particularly as new technological developments such as Dextrostrix made this simpler and automated analysing machines allowed for the quick processing of large numbers of samples in a short period of time.⁷¹ For the most accurate results it recommended taking blood tests two hours after a high carbohydrate meal or oral glucose load (preferably 50g).⁷² This was a modified version of the glucose tolerance test used in the clinical diagnosis of diabetes.

The WHO Committee did not resolve the problem of diagnostic values. As Butterfield had intimated, the Committee recommended 140mg/100ml as diagnostic of diabetes in capillary samples (130mg/100ml in venous samples). The Committee recommended that doctors and public health authorities should regularly examine borderline cases between the 'diabetic' and 'normal' (120mg/100ml capillary or 110mg/100ml venous) who were thought more likely to develop diabetes.⁷³ Again, these levels could be inconclusive in the elderly; glucose tolerance appeared to diminish with age leading some to argue it was not pathological.⁷⁴ Part of the Committee's interest in encouraging screening and epidemiological surveys was to gain more information on the progression from glucose intolerance to diabetes.

⁷⁰ Butterfield, p.72.

⁷¹ WHO, *Diabetes Mellitus: Report of an Expert Committee*, pp.42–44.

⁷² *Ibid.*, p.21.

⁷³ *Ibid.*, p.12.

⁷⁴ Norman S. Hayner, Marcus O. Kjelsberg, Frederick H. Epstein, and Thomas Francis Jr., 'Carbohydrate tolerance and diabetes in a total community, Tecumseh, Michigan', *Diabetes*, 14, 7, July 1965, pp.413–23.

In New Zealand, Christchurch diabetes physician, Dr Donald Beaven, was planning his own epidemiological study to contribute to this overseas evidence. At the postgraduate course, Butterfield, Beaven, Dr Kaye Ibbertson, Dr Ian Prior, and a Medical Officer of Health (unnamed on the programme) had held a panel discussion on current epidemiological studies and screening in New Zealand.⁷⁵ Prior's epidemiological studies had found a high prevalence of diabetes in Maori, but there was less known about Pakeha rates.⁷⁶ Beaven was organising an ambitious population survey of the borough of Rangiora in North Canterbury. As this community was almost uniformly Pakeha, the survey could provide comparative ethnic data to Prior's studies.⁷⁷ Beaven called this an epidemiological 'opportunity unrivalled in the world'.⁷⁸ Moreover, Beaven thought that it would also be able to establish routine procedure for the Health Department to undertake screening nationally.

Hence, despite the significant international uncertainty about testing methodologies and the level of blood glucose that constituted diabetes, Beaven saw that New Zealand surveys might offer a guide, not only for local public health authorities, but also for the rest of the world. His goal was in accordance with the recommendations of the WHO Expert Committee on Diabetes, which argued a lack of information was no reason not to undertake screening programmes.

'It is certain to put Rangiora on the world map of medical information'

In encouraging local public health nurses to volunteer their services for Beaven's diabetes survey, Christchurch Medical Officer of Health L.F. Jepson enthused that the survey was

⁷⁵ 'Diabetes Mellitus: Nature, Epidemiology and Treatment'.

⁷⁶ Prior had completed one small survey of Pakeha in Carterton in 1964: see Chapter One.

⁷⁷ J.T. Murray, E.E. Hannah, J.K. Laing, A.P. Cotter, R.H. Ferrar, H.D.J. Lovell-Smith, R.L. Thompson, L.F. Jepson and D.W. Beaven, 'Diabetes mellitus in European New Zealanders', NZMJ, 69, 444, May 1969, p.271.

⁷⁸ Minutes of the Annual General Meeting of the DANZ, 26 June 1965, p.25, DNZ.

‘certain to put Rangiora on the world map of medical information’.⁷⁹ The appeal of contributing to scientific knowledge while improving public health would inspire widespread community support.

According to a contemporary magazine article, the borough of Rangiora was the ideal ‘guinea pig town’ for the first total community survey of diabetes prevalence in Pakeha adults.⁸⁰ On four Saturday mornings in April 1967, there would be an attempt to test all persons over twenty-one years of age that resided within the borough boundaries, for diabetes.⁸¹ Beaven chose Rangiora for its racial composition, clear geographical borders, proximity to the medical facilities and latest technology at Christchurch and Princess Margaret hospitals, keen local doctors and supportive local service clubs.⁸² He had also obtained £1,000 from the Canterbury Trustee Savings Bank toward the survey costs and further support from the Canterbury Medical Research Foundation and North Canterbury Hospital Board.⁸³ The Health Department provided posters, advertisements and some financial assistance towards hall hire, team transport and tests.⁸⁴ A senior general practitioner, Dr Arthur Cotter, chaired a main co-ordinating committee. This committee consisted of Rangiora’s other three family doctors, representatives from the Princess Margaret Hospital Research Unit, Jepson representing the Health Department, John Murray, Head of the Biochemistry Department at Christchurch

⁷⁹ Jepson to Nurse Inspectors, 4 November 1966, Diabetes – including special surveys, 1965–81, CAVX 2912 CH588 Box 101/ 14/47 (9289), Archives New Zealand, Christchurch (ANZC).

⁸⁰ Dorothy Braxton, ‘Rangiora is proud “guinea pig” town’, *New Zealand Woman’s Weekly*, 30 January 1967, p.4.

⁸¹ A door-to-door census prior to the survey ensured the inclusion of everyone meeting this criterion: Murray et al., p.271. The fifteen Maori and three residents of Chinese descent who participated were not included in the analysis of the results.

⁸² ‘Diabetes Survey’, 1967, (16mm B&W Film) AAPG W3471 6239 9, ANZW. Key service clubs involved were Rotary, the Junior Chamber of Commerce, Round Table, Red Cross, St John, and the Christchurch Diabetes Society.

⁸³ Minutes of the Annual General Meeting of the Diabetic Society of New Zealand, 10 June 1967, DNZ. Beaven established the Canterbury Medical Research Foundation in 1960.

⁸⁴ ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW; CAVX 2912 CH588 Box 101/ 14/47 (9289), ANZC.

Hospital, pharmacist Neil Harrison, Alan Scroggins for the Rangiora Rotary Club, several other service club representatives, and of course, Beaven.⁸⁵

Initial planning discussions between Beaven and the local family doctors centred on technical issues of diabetes screening. The release of the WHO report a few months into these talks meant the doctors altered the original plan for a simple urine test to accommodate the recommendation for blood testing. Jepson argued this meant the survey would be ‘the first one to comply with world standards incorporating the newest techniques’.⁸⁶ Participants would provide a urine sample and a venous blood sample two hours after taking 50g of oral glucose. As such, the doctors had to consider several of the issues around the processing and interpretation of blood tests covered in the WHO report. These included the diagnostic blood sugar level for definite diabetes, the re-examination of borderline cases, and the technological capacity to handle multiple blood specimens in a short time.⁸⁷

Technologies that automated blood sample analysis were changing screening practice. These technologies shifted the emphasis of public health screening from the separate case-finding activities characteristic of communicable disease control, to locating the incipient and often simultaneous presence of chronic disease pathologies.⁸⁸ Christchurch Hospital had one of these new technologies, the AutoAnalyzer. Whereas Dextrostix used a chemical reduction to produce a colour change that indicated a qualitative blood sugar level, the AutoAnalyzer gave much more accurate quantitative measurements as it extracted the glucose by dialysis.⁸⁹ It could also analyse sixty specimens in an hour and run other biochemical tests off the same

⁸⁵ Jepson to Nurse Inspectors, 4 November 1966.

⁸⁶ *Ibid.*

⁸⁷ *Ibid.*

⁸⁸ Stanley Joel Reiser, ‘The Emergence of the Concept of Screening for Disease’, *Milbank Memorial Fund Quarterly/Health and Society*, 56, 4, 1978, p.414; Angela Raffle and J.A. Muir Gray, *Screening: Evidence and Practice*, Oxford, 2007, pp.7–14.

⁸⁹ WHO, *Diabetes Mellitus: Report of an Expert Committee*, pp.42–43.

blood sample.⁹⁰ This multiphasic testing could create savings in both cost and professional time.⁹¹ Beaven and the doctors thus decided to take the opportunity to test for estimations of factors in other health conditions of concern at the time such as uric acid levels, cholesterol and fatty acid levels. According to Jepson, this changed the whole nature of the diabetes detection survey: ‘From all these discussions, what was to be at first a simple public health screening measure has now developed into a large scale scientific approach to the screening of the Rangiora people for these various biochemical tests’. The Rangiora survey was to ‘be the biggest and most detailed screening ever undertaken in this country’ and at the forefront of modern screening practice for chronic disease.⁹²

Over 1966 the main committee developed the procedure for the survey. Each adult in the community would have an appointment to come to the local primary school for a blood test and a packet of glucose with instructions on how and when to take it. They were to pass urine just before leaving home for the appointment and to bring a sample along with them. At their appointment time, participants would fill in a questionnaire on their general health, have their height and weight measured and hand over their urine sample. A venesectionist would then take a blood sample and send the specimens to Christchurch Hospital for analysis on the AutoAnalyzer. The blood results would be ready within ten days for the participant’s nominated doctor to follow-up. A pilot project on 3 December 1966 of 150 randomly selected people confirmed that the venesectionist could take 150 tests in one hour and it would therefore be possible to test at least 90 per cent of the Rangiora adult population.⁹³

⁹⁰ ‘Diabetes Survey’. The Auto-Analyzer, however, did require a highly trained operator: WHO, *Diabetes Mellitus: Report of an Expert Committee*, p.43. Although at Christchurch Hospital, ‘a lad who failed School Certificate’ was apparently capably operating the machine: ‘Notes from Professor Butterfield’s Talk at the Post-Graduate Committee Seminar at Christchurch Hospital, 9 July 1965’.

⁹¹ Reiser, p.414.

⁹² Jepson to Nurse Inspectors, 4 November 1966.

⁹³ *Ibid.*; ‘Diabetes survey trial in Rangiora on Saturday’, *Press* (Christchurch), 1 December 1966.

To achieve the participation goal of 90 per cent, the survey organisers also paid careful attention to publicity and community involvement. A Publicity Sub-Committee consisting of members of the local service clubs oversaw a campaign that included regular newspaper articles, circulars and pamphlet drops, displays at the Agricultural and Pastoral Show, Horse Society Show and Christchurch Show, public meetings, and a radio advertisement sponsored by the Rangiora Businessmen's Association.⁹⁴ A Canvassing Sub-Committee co-ordinated around 100 canvassers who personally approached every household to explain the survey.⁹⁵ Canvassers emphasised the esteem of participating in pioneering medical research, but also the benefits to the individual of early detection. Notes for the canvassers included information that, 'Many patients are found to have had diabetes for up to twenty years before they first go to the doctor or to hospitals with eye troubles, heart attacks, strokes, miscarriages, etc.' and that the screening test was a legitimate public health measure, 'just like the Mass Chest X-Ray campaigns for T.B. control'.⁹⁶ The canvassers distributed printed instructions personalised with individual's appointment date and time, and reinforced these verbally on home visits at least twice before the survey.⁹⁷

Rangiora residents turned out in force on the survey day.⁹⁸ The *Press* (Christchurch) reported that, 'According to Dr Beaven nowhere else in the world has such an effective test been carried out. It was previously considered that voluntary surveys involving urine and blood tests should not be attempted because of a relatively low level of co-operation.'⁹⁹ Low co-operation was a valid assumption considering what participants had to do. While tuberculosis

⁹⁴ Minutes of the Publicity Sub-Committee, 4 October 1966, CAVX 2912 CH588 Box 101/ 14/47 (9289), ANZC.

⁹⁵ Jepson to Nurse Inspectors, 4 November 1966.

⁹⁶ Jepson to Dr W.R. Young, 18 August 1966, CAVX 2912 CH588 Box 101/ 14/47 (9289), ANZC.

⁹⁷ 'The Rangiora Diabetes Screening Committee Value Your Help in This Community Effort', copy of instructions to participants, CAVX 2912 CH588 Box 101/ 14/47 (9289), ANZC.

⁹⁸ By contrast a 1964 mass screening campaign in Auckland attracted only 50 per cent of the district's population over fifteen years of age: see Dunsford, pp.146–7.

⁹⁹ 'Survey of world importance', *Press* (Christchurch), 5 May 1967.

x-ray screening or random Clinistix or Dextrostix diabetes detection drives required little effort, Rangiora residents had to follow a detailed set of instructions that could impinge on their usual eating, toileting and activity routines. On the Saturday morning of their test, participants were to eat 'a light breakfast (not a cooked one)' and then dissolve their packet of glucose in a glass or teacup with soft drink, tea, water or other drink and take this ninety minutes before their appointment time. They had to then empty their bladder, not eat or drink anything else and avoid strenuous exercise. Just prior to coming to the school they had to urinate again, this time half filling a container provided and bring it to the testing centre.¹⁰⁰ Despite these complex instructions, the survey successfully screened 93 per cent of the 2,670 adults of Rangiora. Beaven attributed the high turnout to the 'very high degree of voluntary organisation' and the home visitors' repeat educational visits before the survey.¹⁰¹ A film of the survey produced by the National Film Unit and Christchurch Diabetes Society displayed the scale of the voluntary workforce, organisation and sense of community pride and commitment to the success of the campaign.¹⁰²

The high participation meant the survey results provided useful scientific information. The blood tests found ninety people had a blood sugar reading of over 130mg/100ml on the survey day. After follow-up examinations and glucose tolerance tests, these peoples' doctors diagnosed fifty-seven with diabetes. A further 119 people had blood sugar readings of between 110 and 129mg/100ml and were classified as a 'marginal group'. The community had a diabetes prevalence rate of 4 per cent.¹⁰³ The Rangiora results, like those at Bedford, showed that a high urine sugar reading did not necessarily equate with a blood sugar reading indicative of diabetes; many of these people fell into the marginal group and Beaven's

¹⁰⁰ 'The Rangiora Diabetes Screening Committee Value Your Help in This Community Effort'.

¹⁰¹ Murray et al., pp.274, 272.

¹⁰² 'Diabetes Survey'.

¹⁰³ Murray et al., Jepson and Beaven, p.274.

Medical Unit would monitor them in follow-up studies. Similarly, the Rangiora Survey confirmed an increasing renal threshold with increasing age, finding an excess of undetected diabetes amongst elderly females. Beaven and colleagues determined ‘there was a forty percent chance that diabetics will not have glycosuria even after a glucose load and that their diabetes mellitus will go undetected’.¹⁰⁴ This high false negative rate with urine screening lent further weight to the two-hour post-glucose blood test as the best available in screening for diabetes.

The Rangiora diabetes detection survey, it appeared, would ‘put Rangiora on the world map of medical information’. Professor Butterfield, as Chairman of the Sixth Congress of the IDF, held not long after the survey, paid tribute to ‘New Zealand as the one country ... classified according to the WHO’s criteria’.¹⁰⁵ The survey succeeded in meeting its aims of comparing urine and blood-based tests in community surveys and gathering statistical data. Moreover, its success in engaging the community with the notion of uncovering hidden diabetes demonstrated the high public appeal of screening in the 1960s.

‘The early detection of various diseases all has similar problems’

In 1969 Dr Bryan Christmas of the Health Department’s Division of Public Health, and newly co-opted member of the DANZ’s Medical Advisory Panel, cast doubt about the future of detection campaigns. He told the DANZ’s annual general meeting that ‘the early detection of various diseases all have similar problems’ and proceeded to list a number of issues which

¹⁰⁴ Ibid. For follow-up Rangiora studies, see D.W. Beaven, A.C. Arcus, J.F. Bell, Jennifer R. Smith, ‘Epidemiology of diabetes mellitus’, *NZMJ*, 80, 525, 9 October 1974, pp.291–9.

¹⁰⁵ ‘Film of diabetics’ survey shown’, *Press* (Christchurch), 7 September 1967.

would need to be considered for any screening proposal.¹⁰⁶ What had happened to the co-operation and optimism about mass screening for hidden diabetes so visible in Rangiora?

After the Rangiora survey, diabetes societies expected the Health Department to institute mass screening nationally, but instead found it would only provide discretionary support for their detection drives. Some of the larger societies held regular detection drives at Agricultural and Pastoral shows and other public events. Largely due to Nesfield's zeal for the issue, the Auckland Society in particular focused on screening. In 1967, Nesfield suggested that the Health Department should routinely offer diabetes testing with the Auckland mobile x-ray units. The Auckland Medical Officer of Health responded that 'the Health Department has no immediate plans to provide free diabetes testing facilities on a large scale'.¹⁰⁷ The Department, however, would provide support for the Auckland Society to conduct tests during the 'Partners in Health' World Health Week. The tests proved so popular they overshadowed other exhibits.¹⁰⁸ Yet, by the end of 1968, the Auckland Society found the Health Department rejecting its requests to cover the costs of Dextrostix for other detection drives, ostensibly because of budgetary constraints.¹⁰⁹

While the Department claimed to appreciate local screening programmes were 'most certainly good preventive medicine', health officials were beginning to doubt their actual benefits.¹¹⁰

This was evident when the pharmaceutical company, Hoechst, presented the Department and the DANZ with a proposal for a national detection campaign to run over 1969. The

¹⁰⁶ Medical Advisory Report to the Annual General Meeting of the DANZ, 14 June 1969, DNZ. One of the main reasons the Panel had co-opted a Health Department representative was to work more closely on 'specific proposals regarding diabetes prevention', in particular early detection and education initiatives: Report of the Medical Advisory Panel to the Annual General Meeting of the DANZ, 8 June 1968, DNZ.

¹⁰⁷ 'No plan yet for diabetic tests', *N.Z. Diabetic Review*, 5, 4, May 1967, p.5.

¹⁰⁸ S.F. Hovey to Kennedy, 28 August 1968, Projects, exhibitions, displays – World Health Organisation [sic], 1961–67, BAAK 19860 A358 99/c 17/30/1 part 1 (8789), ANZA.

¹⁰⁹ Christmas to Nesfield, 17 December 1968, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

¹¹⁰ Ibid.

centrepiece of the campaign would be a series of advertisements which suggested middle-aged and overweight people should visit their general practitioner for a test, but the company also wanted to collaborate on public detection drives.¹¹¹ The lay societies responded positively; Auckland shifted its diabetes awareness week to coincide with the release of the advertisements and the DANZ's Executive encouraged other societies to liaise with their local medical officers of health on detection campaigns.¹¹² Hoechst assumed it had approval from the DANZ and the Health Department, and that District Health Offices would supply personnel and practical support for the campaigns.¹¹³ When Christmas learned of this from the concerned Medical Officer of Health for Dunedin, F.A. de Hamel, he replied that this was entirely incorrect and not in line with his current thinking on diabetes screening.¹¹⁴ De Hamel had recently taken overseas study leave to investigate screening procedures and was in the process of formulating recommendations for future Department policy. He recommended 'the Department should go cautiously at this stage in our knowledge ... while diabetic surveys undoubtedly raise the status of the Public Health Department in the eyes of the public', it did not adequately know the value of early detection.¹¹⁵ Christmas agreed that extensive screening of asymptomatic people was of uncertain worth and the Department preferred to support preventive education programmes.¹¹⁶

At the DANZ's 1969 annual meeting, the Medical Panel discussed its position on detection drives. While generally supporting the testing programmes of local societies, it argued they needed standardisation and that societies should consult the Medical Panel before they commenced any campaigns. In his capacity as Health Department representative, however,

¹¹¹ F.K. Moss to Kennedy, December 1968, ADBZ 16163 H1 1237/ 131/20/6 (45365), ANZW.

¹¹² Minutes of a Meeting of the Executive of the DANZ, 3 March 1969, p.2, DNZ.

¹¹³ F.A. de Hamel to Kennedy, 22 May 1969, Diseases – Diabetes, 1965–75, AAFB 632 W2969 35/ 131/20 (44534), ANZW.

¹¹⁴ Christmas to de Hamel, 3 June 1969, AAFB 632 W2969 35/ 131/20 (44534), ANZW.

¹¹⁵ De Hamel to Kennedy, 22 May 1969.

¹¹⁶ Christmas to de Hamel, 3 June 1969.

Christmas relayed that, ‘from the public health perspective’, there were several problems with the early detection of diabetes and other diseases; tests needed to be easy, economical, not give false positives or negatives, and there needed to be sufficient diagnostic and treatment facilities to cope with any new cases found. He believed ‘screening for diabetes at present is best aimed at those at high risk and we must not expect such dramatic results with chronic disease as in the case with infections’.¹¹⁷ The Department was more likely to support the DANZ in education programmes, ‘say, directing the public’s attention to the hazards of overweight’, rather than screening.¹¹⁸ Dunedin specialist Dr Jack Kilpatrick argued that it was ‘namely those with diabetic relatives, and obese persons’ that the societies’ should aim screening at.¹¹⁹

Internationally, in the late 1960s medical academics and health officials had begun to question the assumption that screening for asymptomatic disease was always beneficial and a wise use of health resources. As with diabetes, the preceding two decades had seen the introduction of a range of population-based screening tests and programmes to detect early signs of disease, largely due to faith in their efficacy, expert or popular advocacy, and advances in technology.¹²⁰ In 1968, two major publications provided a critical analysis of these developments. In the United Kingdom, the Nuffield Provincial Hospitals Trust had established a working group headed by Thomas McKeown, Professor of Social Medicine at the University of Birmingham, which examined screening for a variety of conditions. The resultant collection of essays found many existing or proposed screening programmes had insufficient evidence to prove they were medically effective or the best use of financial and

¹¹⁷ Medical Advisory Report to the Annual General Meeting of the DANZ, 14 June 1969, DNZ.

¹¹⁸ Christmas to de Hamel, 3 June 1969.

¹¹⁹ Medical Advisory Report to the Annual General Meeting of the DANZ, 14 June 1969, DNZ.

¹²⁰ Jowitt, pp.214–5.

human resources in health care.¹²¹ The WHO also released a monograph that established ten criteria for assessing screening projects – including those Christmas had relayed to the DANZ – which became highly influential amongst health officials and policy-makers in the 1970s and beyond.¹²²

In the case of mass detection of diabetes, Professor Butterfield wrote an essay for the Nuffield publication that highlighted issues with diagnosis. The 1965 WHO Report had by no means settled debate on diagnostic blood sugar values and Butterfield believed it could take up to a decade to work out ‘an accepted age adjusted level’.¹²³ Two-hour blood sugar values could vary across tests, particularly outside controlled laboratory conditions.¹²⁴ Although Butterfield stated the chance was small, this meant there would be the possibility to miss some cases and misdiagnose others with diabetes.¹²⁵ De Hamel had expressed concerns about the ‘unnecessary and undesirable anxiety on the part of the public’ that Hoechst’s advertisements might induce; the potential of misdiagnosis was even more undesirable considering residual social stigma associated with the disorder and the continued difficulties people with diabetes had in obtaining insurance and employment.¹²⁶

Critics of mass screening for diabetes also questioned whether there was enough evidence to show that current methods of treatment were effective for the adult-onset cases screening was most likely to find. People with juvenile diabetes typically had acute symptoms and sought out diagnosis. Their treatment with insulin had resulted in a definitive decline in death rates,

¹²¹ Thomas McKeown, ed., *Screening in Medical Care: Reviewing the Evidence: A Collection of Essays*, Nuffield Provincial Hospitals Trust, London, 1968.

¹²² J.M.G. Wilson, and G. Junger, *Principles and Practice of Screening for Disease*, WHO Public Health Papers No.34, Geneva, 1968; Jowitt, p.217.

¹²³ Butterfield, p.74.

¹²⁴ For those who had abnormal results, Murray and colleagues compared their two-hour values under survey conditions with those obtained in their follow-up glucose tolerance test in hospital and found a 6mg difference. The researchers did not consider this a significant methodological issue: Murray et al., p.273.

¹²⁵ *Ibid.*, pp.72–73.

¹²⁶ De Hamel to Kennedy, 22 May 1969.

but the death rates for older age groups had undulated or were rising.¹²⁷ In 1968, Butterfield concluded on the evidence around treatment that, ‘the crucial question is the treatment of diabetic complications: better understanding of the metabolic abnormality underlying them – it may not be simply hyperglycaemia – and means of correcting it would be a major advance’.¹²⁸ While people with adult-onset diabetes managed the condition through diet and exercise, some also took insulin and many took oral hypoglycaemic medication. In his 1972 publication *Effectiveness and Efficiency: Random Reflections on Health Services*, Professor Archie Cochrane, director of the British Medical Research Council’s Epidemiology Research Unit, called into question the value of these drugs. He cited equivocal evidence from two clinical trials that had just reported results. The University Group Diabetes Program study in the United States had found that the common drugs Tolbutamide and Phenformin were dangerous (the former associated with increased risk of cardiovascular deaths and the latter with lactic acidosis), while insulin had no effect.¹²⁹ The other trial, an eight-year follow-up of borderline and newly diagnosed patients from Butterfield’s Bedford survey, which compared diet and oral medications, found fewer cardiovascular deaths and ‘events’ in the Tolbutamide group than in the placebo group. Counterweighing this contradictory evidence Cochrane concluded that ‘the treatment of mature diabetics would seem to be an example of the large scale use of ineffective and possibly dangerous therapies in a particularly inefficient way’.¹³⁰

The inefficiency of treatment facilities was a major concern for those who questioned investment in mass screening. Cochrane critiqued at length the ‘idea of the chronic out-patient’: treated continuously at hospital diabetes clinics instead of going for consultation then back to the care of their general practitioner, such patients had caused unsustainable clinic

¹²⁷ A.L. Cochrane, *Effectiveness and Efficiency: Random Reflections on Health Services*, London, 1972, p.54.

¹²⁸ Butterfield, p.76.

¹²⁹ Cochrane, pp.54–55.

¹³⁰ *Ibid.*, p.56.

overcrowding in Britain.¹³¹ Butterfield's experience with the Bedford survey had also convinced him of the need for investment in treatment resources prior to initiating screening programmes as the influx of new cases had quickly overwhelmed the existing diabetes clinic. Reflecting on the Nuffield report in their 2007 book *Screening: Evidence and Practice*, Dr Angela Raffle and Sir Muir Gray noted how that report had 'challenged the widespread assumption that screening would inevitably lead to a reduced healthcare costs' as it could also become 'a major lost opportunity for using resources in a more beneficial way'.¹³²

Despite such concerns, in New Zealand, diabetes detection drives remained popular in the 1970s. Deborah Jowitt has argued in her doctoral thesis on Hepatitis B policy in New Zealand that the advent of a more critical approach to screening amongst health officials 'did not mean that all members of the medical profession accepted [the criticisms] or that interest groups and individuals did not continue to advocate strongly for the introduction of screening programmes'.¹³³ In regards to diabetes, individuals and interest groups took it upon themselves to organise screening.¹³⁴ The Auckland Society held detection drives at its annual 'Diabetes Week'. Technicians undertook the actual testing and lay volunteers recorded information about the person tested, a procedure Nesfield claimed to be 'highly successful'.¹³⁵ Nevertheless, there were problems with doctors disregarding abnormal results or not getting diagnostic information back to the Society.¹³⁶ The Medical Panel thought the Society needed more tact in enlisting doctors' co-operation before screening tests, but also expressed concern

¹³¹ Ibid.

¹³² Raffle and Gray, p.12.

¹³³ Jowitt, p.218.

¹³⁴ Butterfield had also expressed concern that the British Diabetic Association's 'very lively interest in diabetic screening' could pose 'a serious hazard' to the accumulation of knowledge and wanted the media to make sure 'affairs do not get out of hand': Butterfield, p.79.

¹³⁵ Minutes of a Meeting of the Executive of the DANZ, 14 September 1970, p.1, DNZ.

¹³⁶ The Society sent the person's doctor a form outlining that their test result indicated they might have diabetes and recommending a glucose tolerance test. An example c. 1976 is available in, D.W. Beaven Papers, Accession #195, 36788, Macmillan Brown Library (MBL).

about general practitioners' apparent ignorance of the importance of diabetes.¹³⁷ These issues became pressing in 1972 as Auckland purchased their own reflectance meter, a device used to read and quantify Dextrostix results, and planned to expand their testing. In Christchurch, Beaven, who was still confident that screening for pre-symptomatic disease was the future of progressive medicine, attempted to make random detection drives more scientific and include adequate follow-up procedures.¹³⁸ For the 1971 World Health Day commemorating the fiftieth anniversary of the discovery of insulin, Beaven's Medical Unit at Princess Margaret Hospital worked with the District Health Office and Christchurch Diabetes Society to provide free screening tests in the central city.¹³⁹ In 1974 these groups, and others, collaborated again on a detection survey at the Agriculture and Pastoral Summer Show.¹⁴⁰ When the DANZ began planning for its first 'National Diabetes Week', to be held in 1976, it encouraged all societies to organise detection drives.¹⁴¹

By this stage, the DANZ Medical Panel intervened in what it called 'the willy nilly holding of detection drives' and set out a policy for local societies.¹⁴² It stated, 'they should be undertaken only where they are coupled with a specific scientific study and where there is proper follow up of identifying patients'. The Panel told the DANZ, however, that it had 'no objection to detection vans at shows etc. in an effort to increase membership'.¹⁴³ The Auckland and Taranaki Societies continued to conduct detection drives that were not in

¹³⁷ J.A. Kilpatrick to D. Hanna, 24 October 1972, D.W. Beaven Papers, Accession #195, 36709, MBL.

¹³⁸ D.W. Beaven, 'Man's Changing Ideas of Disease: Evolution for Survival', in D.W. Beaven and B.H. Easton, eds, *The Future of New Zealand Medicine: A Progressive Viewpoint*, Christchurch, 1974, pp.8–10.

¹³⁹ Health Education and Publicity – District Health Education Committee – Christchurch, 1962–72, ADBZ 16163 H1 2020/ 34/45/1 (39891), ANZW.

¹⁴⁰ M.H. Abernethy, C. Andre, D.W. Beaven, H.W. Taylor and G. Welsh, 'A random blood sugar diabetes detection survey', *NZMJ*, 593, 86, 10 August 1977, pp.123–6. See also CAVX 2912 CH588 Box 101/ or 14/47 (9289), ANZC.

¹⁴¹ Annual Report of the DANZ for the Year Ended 31 December 1975, p.2, DNZ.

¹⁴² Minutes of the Annual General Meeting of the DANZ, 13 March 1976, p.2, DNZ.

¹⁴³ *Ibid.*

accordance with the Panel's policy throughout 1976, leading the Panel to strengthen its position that 'screening was best done by a doctor in his own practice'.¹⁴⁴

Perhaps most problematic with the fervour for detection drives was the uncertainty about diagnostic criteria. The Rangiora survey had used the WHO's provisional diagnostic criteria to much fanfare. With more surveys around the world, it became increasingly apparent that there was a continuous distribution of blood glucose levels making cut off points somewhat subjective. In 1975, American epidemiologist Kelly West found the varying diagnostic values in use at that time meant the same population data could suggest a prevalence of anything from 5 to 30 per cent.¹⁴⁵ Such variance contributed to the United States National Diabetes Data Group and the WHO Second Expert Committee on Diabetes Mellitus reviewing the diagnostic criteria in the late 1970s. These reviews, published in 1979 and 1980, provided the first widely accepted classification of diabetes into Type I insulin-dependent diabetes (IDDM) and Type II non-insulin-dependent diabetes (NIDDM). They also created a new category of impaired glucose tolerance (IGT). These were the borderline cases – 'asymptomatic diabetics', 'latent diabetics' or 'prediabetics' – found in detection drives. With the new classifications, the two-hour diagnostic blood glucose level for diabetes increased from 130mg/100ml to 180mg/100ml in venous samples.¹⁴⁶ This suggested detection drives that had used the previous criteria, and even scientific surveys like at Rangiora, may have misdiagnosed people with diabetes who in the 1980s would have IGT.¹⁴⁷ Moreover, the WHO

¹⁴⁴ Minutes of a Meeting of the Medical Advisory Panel of the DANZ, 18 November 1976, p.1, DNZ.

¹⁴⁵ H. Keen, 'Problems in the Definition of Diabetes Mellitus and Its Subtypes', in J. Köbberling and R. Tattersall, eds, *The Genetics of Diabetes Mellitus Proceedings of the Sero Symposium, Volume 47*, London, 1982, p.2.

¹⁴⁶ The levels were now expressed as 10.0mmol/l for venous whole blood or 11.0mmol/l (200mg/100ml) for capillary whole blood. The recommended glucose load two hours prior to testing was also increased from 50g to 75g. This would make levels about 15mg higher: see WHO, *WHO Expert Committee on Diabetes Mellitus: Second Report*, Technical Report Series No.646, Geneva, 1980, pp.9–10.

¹⁴⁷ Keen, pp.3–5. In a report on a survey of diabetes in Christchurch undertaken in 1982–83 using the new WHO and NDDG criteria, the authors compared the results to those in Rangiora and argued many of those diagnosed with diabetes in the Rangiora survey would now be classified as having IGT: C.R.S. Brown, P.N. Hider, R.S.

still considered that the new diagnostic levels ‘may not be universally applicable’ and were ‘somewhat arbitrary’, based on the finding that complications were rare in populations under this level.¹⁴⁸

The harm of misdiagnosis with diabetes may not have been as dangerous as earlier critics had suggested, but was not necessarily without consequence. While New Zealand, like most countries, banned Phenformin in the late 1970s, the risks of lactic acidosis were largely to people who already had impaired cardiovascular and renal function.¹⁴⁹ Outside of the United States, most authorities discredited the findings of the University Group Diabetes Program on the cardiovascular risks of Tolbutamide as not statistically significant and potentially biased as the higher death rates came from only two universities involved in the study. European authorities and New Zealand’s Medical Panel continued to advise using Tolbutamide if clinically indicated, which usually did not include asymptomatic patients.¹⁵⁰ Alternatively, if a person tested negative for diabetes, but still had risk factors for its development, they may have gained a false sense of security.

The low risk of physical harm does not discount the possibility of psychological or social harm resulting from detection drives. The rationale for introduction of the term IGT was that, although it entailed an increased risk of progression to diabetes and atherosclerosis, the

Scott, W.A. Malpress, D.W. Beaven, ‘Diabetes mellitus in a Christchurch working population’, *NZMJ*, 97, 760, 25 July 1984, pp.487–9.

¹⁴⁸ WHO, *WHO Expert Committee on Diabetes Mellitus: Second Report*, p.11. Diagnostic criteria have since moved down slightly but not to the 1965 levels: see ‘NZSSD Position Statement on the diagnosis of, and screening for Type 2 Diabetes’, September 2011, URL: <http://www.nzssd.org.nz/HbA1c/1.%20NZSSD%20position%20statement%20on%20screening%20for%20type%202%20diabetes%20final%20Sept%202011.pdf>, accessed 25 September 2014.

¹⁴⁹ I.J. Simpson, J.W. Henley and D.N. Sharpe, ‘Lactic acidosis associated with Phenformin therapy in diabetes mellitus’, *NZMJ*, 79, 508, 13 February 1974, pp.645–8.

¹⁵⁰ Medical Advisory Panel Report to the DANZ Annual General Meeting, 12 June 1971, p.1, DNZ; Dr Bob Smith, Personal Communication, 3 June 2011. For more on the University Group Diabetes Program trial, see Greene, pp.115–48; Harry Marks, *The Progress of the Experiment: Science and Therapeutic Reform in the United States, 1900–1990*, New York, 1997, pp.197–228.

severity of hyperglycaemia was not believed to be in accordance with the ‘social, psychological and economic sanctions’ which came with the diagnosis of diabetes.¹⁵¹ Despite diabetes societies’ efforts to promote people with diabetes as productive citizens, in a 1977 newspaper article the DANZ President Trevor Gollins called people with diabetes ‘forgotten people’. He relayed how ‘cases of discrimination [in employment opportunities] for no good reason do arise’ and that, ‘Because there is a treatment for it most people think it’s over and done with after detection. So despite the fact that they have to live pretty closely regimented lives, diabetics do not have the sympathy of the populace.’¹⁵² Clearly, the message of publicity inducing people to participate in detection campaigns – that a person with diabetes could have ‘a normal and useful life’ – underplayed the difficulties they might face after diagnosis.¹⁵³

By the 1980s, there was much wider recognition of the need to evaluate these sorts of cost benefits of screening for diabetes. The WHO’s 1980 expert committee noted that while, ‘most diabetes specialists believe that the early discovery of diabetes and the effective control of hyperglycaemia reduces morbidity’, there was ‘considerable disagreement on the usefulness of community screening programmes for early diagnosis’.¹⁵⁴ Two years earlier, a major American workshop had set recommendations for diabetes screening based on the current state of knowledge regarding the key justification for screening: that treatment in the asymptomatic stage would result in better outcomes than if delayed until symptoms appeared. The only population group where the workshop considered this was the case was pregnant women; aggressive blood glucose control of diabetes in pregnancy definitively improved perinatal mortality. There was, however, still ‘no definite evidence that treatment to regulate

¹⁵¹ D.W. Beaven, P.J. Dunn, R.B. Elliott, P. Fleischl, D.M. Hanna, J.A. Kilpatrick, R.B.W. Smith and M.H. Watson, ‘A new international classification of diabetes mellitus’, *NZMJ*, 93, 683, 13 May 1981, p.305.

¹⁵² ‘Forgotten people – the disease that rules their lives’, *Truth*, 25 January 1977.

¹⁵³ Barnett, p.311.

¹⁵⁴ WHO, *WHO Expert Committee on Diabetes Mellitus: Second Report*, p.9.

blood sugar levels is effective beyond relieving symptoms and controlling acute metabolic disturbances’, which did not affect an asymptomatic person.¹⁵⁵ While evidence accumulated to support the positive effects of keeping blood sugars as close to normal as possible on the progression of long-term complications, it was not until the 1990s that prospective clinical trials confirmed that this would prevent these complications.¹⁵⁶ In 1980 the WHO Expert Committee, however, still suggested that there might be advantages in combined public education and screening campaigns due to the fact that people found were often not asymptomatic, but did not recognise their symptoms. In any case, it argued that, ‘Screening should always be accompanied by cost-benefit analysis.’¹⁵⁷

While health officials took this advice on board, detection drives were something they found difficult to control. In the early 1980s, Lions clubs began supplying diabetes societies with detection caravans for their awareness campaigns.¹⁵⁸ Additionally, many saw the advent of home blood glucose testing at this time as a reasonable justification for lay people to conduct random finger-prick tests in community settings. The Health Department’s Director of the Division of Health Promotion, Dr R. Campbell Begg, informed a Lion’s representative in 1983 that,

The department’s and the profession’s attitude to screening for diabetes is generally one of caution because experience has often shown that unless it is terribly well controlled with the appropriate backup facilities that not a great deal is achieved....

¹⁵⁵ Charles A. Herron, ‘Screening in diabetes mellitus: report of the Atlanta Workshop’, *Diabetes Care*, 2, 4, 1979, p.359.

¹⁵⁶ The ability to maintain ‘normal’ blood sugars with diabetes, and for it to be prospectively studied, to a large extent required the development of new technologies such as home blood glucose monitoring, insulin pumps and the HbA1C test to gauge long-term control. For Type I, see the Diabetes Control and Complications Trial Research Group, ‘The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin dependent diabetes mellitus’, *New England Journal of Medicine*, 329, 1993, pp.977–86; for Type II, the United Kingdom Prospective Diabetes Study (UKPDS) ran from 1977–1997 and resulted in numerous publications; a bibliography is available at URL: <http://www.dtu.ox.ac.uk/UKPDS/>, accessed 3 January 2015. The UKPDS also confirmed the importance of intensive control of hypertension in reducing cardiovascular disease in people with diabetes. There were continued concerns, however, about the safety and achievability of maintaining normal blood sugars, in all patients, as hypoglycaemia and weight gain was more common, which both contributed further risks to cardiovascular health.

¹⁵⁷ WHO, *WHO Expert Committee on Diabetes Mellitus: Second Report*, p.20.

¹⁵⁸ Details are recorded in the DANZ Annual Reports for 1982, 1983 and 1984.

[and] I think the promotion of awareness is the important feature to which a service club could well direct its attention.¹⁵⁹

Diabetes society detection drives did focus more on targeting at-risk groups, conceived at this time as those with a family history and those over forty years old, but this could be due to cost restraints as much as medical advice.¹⁶⁰ Throughout the 1980s, diabetes nurses also questioned the appropriateness of lay people conducting community screening. While reflecting a degree of professional self-interest (the specialisation of diabetes nurses will be discussed in the next chapter), nurses had real concerns about cross-infection with blood-borne diseases (namely AIDS and Hepatitis B), a lack of indemnity insurance and standardised procedures.¹⁶¹ The DANZ did develop a public blood screening protocol, but it could only ‘strongly’ recommended that societies follow it.¹⁶²

Thus, while health officials in New Zealand, and internationally, adopted a more critical attitude towards screening for diabetes in the 1970s and 1980s, many diabetes advocates continued to promote detection in the community. From a public health perspective, population screening did not appear to represent the best use of health care resources or offer proven benefits in health outcomes. The Health Department and the DANZ’s Medical Panel came to believe screening for diabetes should be risk-based and the responsibility of general practitioners who could provide follow-up care; improvement of care, and raising awareness about diabetes’ symptoms and risk factors became priorities. Although diabetes societies gradually ceded to the Panel’s advice to target their detection efforts to at-risk people/groups,

¹⁵⁹ R. Campbell Begg to Graeme H. Bridge, Diseases – Diabetes, 1981–84, ABQU 632 W4415 267/ 131/20 (56669), ANZW.

¹⁶⁰ Jackie Short, ‘Proposed National Awareness Week: Diabetic Association / Lions N.Z. Joint Project’, 29 August 1984, p.1, DNZ.

¹⁶¹ Mary Robinson to Malcolm Watson, 22 June 1987; Pat Carlton to George Salmond, 15 December 1987, Primary Health Care – Diabetes, 1986–90, ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW.

¹⁶² Annual Report of the New Zealand Diabetes Association for the Year Ended 31 December 1988, p.1, DNZ.

as an adjunct to awareness campaigns, undoubtedly stalwarts like Nesfield still believed they were performing an important public health activity in uncovering ‘hidden diabetics’.¹⁶³

Conclusion

Just as had been the case with the Pap smear for cervical cancer and mass miniature radiography for tuberculosis, the availability of new diagnostic technologies provided a major impetus for diabetes detection campaigns.¹⁶⁴ While surveys to uncover undiagnosed cases of diabetes began in the United States following the 1946 Oxford Massachusetts epidemiological study, it was only in the latter 1950s when urine test strips became available that mass detection took off on a large scale in Western countries.¹⁶⁵ New Zealand medical officers of health, drawing on overseas survey experience, surveyed their local health districts from the early 1960s, in a largely autonomous, ad hoc fashion. They preached the benefit of early detection with little explanation of the reality of managing the condition once found. With news of a more accurate blood-testing product, Dextrostix, the enthusiasm for detection campaigns accelerated. No one was more enthusiastic about the possibilities of Dextrostix than John Nesfield of the Auckland Diabetic Society. In his view, screening for hidden diabetes was a matter of ‘national health and the economic welfare of the community’.¹⁶⁶ Ruffling the feathers of some health officials, Nesfield took it upon himself to bring the new technology to New Zealand and organise a pilot detection drive to encourage the Health Department to adopt mass screening.

¹⁶³ The Auckland Society used a quiz for people to determine if they might be a ‘hidden diabetic’ and should get a free test from the Society: see Copy with letter Nesfield to Christmas, 20 June 1970, International Health – WHO – World Health Day, 1970–73, AAFB 632 W2788 93/ 332/2/14 (39929), ANZW.

¹⁶⁴ Bryder, pp.7–31; Dunsford, p.100.

¹⁶⁵ Mauck, pp.210–1.

¹⁶⁶ Nesfield to Kennedy, 14 May 1965.

Encouragement from international authorities, and the potential for New Zealand to lead the world, also enthused the Health Department and the DANZ's medical experts to conduct diabetes surveys. Following Professor Butterfield's visit to Christchurch and the release of the WHO Expert Committee Report on Diabetes in 1965, Beaven's plans for New Zealand's first total community survey of diabetes prevalence in the Pakeha population, would also be the one of the first to use new diagnostic criteria and the two-hour post-glucose load blood testing technique. The 1967 Rangiora diabetes detection survey thus provided important statistical and scientific information that contributed to epidemiological understanding of the disorder.¹⁶⁷ The widespread community involvement and co-operation between voluntary organisations, health authorities, doctors and researchers suggests there was little concern that mass detection was not a wise investment in human and financial resources, or that it posed drawbacks for the individual.

When the Minister of Health, Don McKay, told the DANZ in 1966 that 'the question of undiagnosed diabetics should be of concern to the whole community', and that his Department would undertake detection campaigns, he implied that the DANZ had a role to play.¹⁶⁸ Lay diabetic societies saw finding undiagnosed people with diabetes as an extension of their efforts in self-help and thus believed they had a legitimate claim to undertake screening, even if they thought the government should subsidise it. Detection drives, however, came to trouble the Health Department, which expressed a new view on screening following the critical challenges of overseas experts in the late 1960s. This view, which persisted throughout the 1970s and beyond, expressed doubt about the benefits of mass screening for diabetes in light of inadequate follow-up, and treatment and diagnostic uncertainties.

Nevertheless, these factors did not quash the keenness of lay societies to continue their

¹⁶⁷ Kelly West, *Epidemiology of Diabetes and its Vascular Lesions*, New York, 1978, pp.150–1.

¹⁶⁸ Minutes of the Annual General Meeting of the DANZ, 11 June 1966, p.1, DNZ.

detection drives. As Departmental and the DANZ Medical Panel support for population screening diminished in favour of risk-based screening in general practice, detection drives became targeted, awareness-raising activities, with local societies often drawing on the resources of other voluntary bodies. The screening debate, however, would continue to evolve with shifting political and medical concerns about Maori and Pacific health, and will be returned to in Chapter Six. From the late 1970s, however, the education of people with diabetes and their health care providers, as the next chapter will elaborate, provided a new focus for state and voluntary sector collaboration.

CHAPTER FOUR

‘Educating diabetics and their families towards self-sufficiency’: the diabetes education movement, 1970s–1980s

While instructing patients about diet, testing urine sugar and self-administering insulin or medication were well-established parts of diabetes treatment by the 1970s, from this point onwards, diabetes specialists in the Western world promoted a new management philosophy. The new approach configured the person with diabetes as an active and integral participant in the diabetes management team, replacing the earlier idea that he or she should be a passive, compliant, recipient of his or her doctor’s intermittent instruction. Diabetes education took new forms: education programmes were structured and reviewed, and utilised counselling techniques, group sessions, multimedia and patient bio-feedback. These changes aimed not only to improve knowledge, but also to motivate patients to make behavioural and attitudinal changes. As the first official diabetes nurse educator in New Zealand, Alison Helm, wrote in a 1977 journal article, ‘The Diabetes Nurse Educator, with this goal in mind, and with the medical profession and dietitians will be required to teach them everything they are capable of learning if self-sufficiency is to be their objective.’ From Helm’s perspective, ‘educating diabetics and their families towards self-sufficiency is an “idea whose time has well and truly come”’.¹

The timing of the diabetes education movement reflected broader changes in the social relations of medicine. Yet, some scholars have understood this education as reinstating ‘traditional medical values’ and ‘medical imperialism’. In this view, patients gained little autonomy and were co-opted into behavioural modification that separated having diabetes

¹ Alison Helm, ‘The Christchurch Hospital diabetes educational programme’, *New Zealand Nursing Journal*, 70, 7, July 1977, p.31.

from its social context and suggested poor health outcomes were, as implied in the past, the result of patient non-compliance.² Conversely, Martin Moore has argued that despite an increasingly patient-centric discourse, the trend doctors initiated in this period was about disciplining professional – not patient – behaviour. In his account, an expanded health care team and shift to more community-based care contributed towards the greater standardisation and monitoring of professional practice. In turn, these developments emphasised a conception of ‘patient-as-biosigns’, with even patient well-being reduced to a checkbox in a bureaucratic system.³ Both these interpretations imply professional insensitivity to patient views.

By shifting the gaze to the involvement of consumer groups, working with health professionals in shaping new community-based educational services in New Zealand, this chapter suggests the motivating factor behind patient education was not social control. This is not to say that professional politics were not also important in the New Zealand context. Despite references in diabetes historiography to the significant roles of nurses and dietitians, their actual perspectives have received little attention.⁴ This chapter will thus consider their views in addition to those of specialists, health administrators and general practitioners, primarily in relation to the country’s first diabetes education centre in Christchurch. It further examines multidisciplinary relationships through the new health professional organisation, the

² Laurie J. Brown, ‘Organizational Influences on Diabetes Related Hospitalization’, PhD thesis, University of Canterbury, 1988, pp.178–96. This argument is similar to the ‘anti-diabetic theme’ some historical accounts have argued has been a continuous characteristic of professional views of patients: Elizabeth Lane Furdell, *Fatal Thirst: Diabetes in Britain until Insulin*, Leiden, 2009, p.167; see also Dan Hurley, *Diabetes Rising: How a Rare Disease Became a Modern Pandemic, and What to Do about It*, New York, 2010, pp.43–64. The social control interpretation of modern diabetes education was also a reaction to physicians’ accounts which suggested this education was a revolution in diabetes management. The revolutionary view is inferred in some recent general histories of diabetes, for example, see Robert Tattersall, *Diabetes: The Biography*, Oxford, 2009, p.197. On the history of patient ‘non-compliance’ as a field of study, see Jeremy Greene, ‘Therapeutic infidelities: “noncompliance” enters the medical literature, 1955–1975’, *Social History of Medicine*, 17, 3, 2004, pp.327–43.

³ Martin Moore, ‘A Question of Control? Managing Diabetes and its Professionals in Britain, 1910–1994’, PhD Thesis, University of Warwick, 2014, pp.246–7, 257–60.

⁴ For one of the few examples which mentions the intersections between nurses’ professional interests and the new diabetes education, see Helen Valier and Roberta Bivins, ‘Organization, Ethnicity and the British National Health Service’, in Jennifer Stanton, ed., *Innovations in Health and Medicine: Diffusion and Resistance in the Twentieth Century*, London, 2002, pp.37–63.

New Zealand Society for the Study of Diabetes (NZSSD) and its efforts to develop professional diabetes educator training. Firstly, however, the chapter will outline some of the concerns patients and professionals had about diabetes education in New Zealand leading up to the quest for ‘patient self-sufficiency’ to elucidate some of the motivations for a change of approach.

‘Too much is left to be found out by hard experience’

In 1962, an Otago University medical student interviewed a variety of people with diabetes and their families about how they coped with the disorder. He found that only one of his ‘subjects felt that she had received sufficient instruction during the course of her disease; the others were unanimous that too much is left to be found out by hard experience’.⁵

Physicians reflecting on the nature of diabetes services in the 1960s and 1970s have often noted that patient education was absent. In 1997, remembering back to his time as a physician at Middlemore Hospital in the 1960s, Dr Dennis Hanna remembered newly diagnosed people with diabetes, who required insulin, being ‘admitted “for stabilisation”. Diabetes education had not been invented.’⁶ This was not entirely true. In most major hospitals, doctors and nurses provided some informal education on the wards, while dietitians gave instruction in outpatient clinics or on the wards. District nurses sometimes taught patients how to use insulin in their homes but, particularly if they were elderly, might instead have administered injections for them. Wellington diabetes specialist Dr Bob Smith has described how, in his early career in the 1960s and 1970s, ‘diabetes care was very patchy’. He recollected that ‘few

⁵ ‘Social and educational aspects of diabetes mellitus’, Preventive Medicine Dissertation, University of Otago, 1962, p.34. The University of Otago requests anonymous citation of dissertations in this collection.

⁶ Dennis Hanna, ‘Reflections on Medicine in the 1960s’, in David Scott, ed., *Middlemore Memories: The First Fifty Years of Middlemore Hospital as Recalled by the People Who Were There*, Auckland, 1997, p.60.

GPs [general practitioners] were greatly interested and many hospitals did not have diabetes clinics', so 'most people starting on insulin were admitted to hospital for education'.⁷

Not only patients required education: general practitioners and nurses were often underprepared for dealing with patients with diabetes. In an interview conducted for the purpose of this thesis, retired diabetes nurse educator Pat Carlton could recall very little information about diabetes during her original nurse training in the 1960s.⁸ Lee Brehaut (nee McLeod), a president of the national diabetes association in the 1980s, remembered that when her fiancé was diagnosed with diabetes in the early 1970s in the small town of Oamaru nobody knew anything about the disorder. They relied on his family doctor, who first put him on tablets although he actually required insulin. It took four years before he could see a specialist, and she recalled feeling totally lost trying to deal with his day-to-day care. The struggle contributed to the end of their relationship.⁹ Russell Finnerty joined his local diabetes society to access information about the disorder that he could not get through the health services.¹⁰

While these informants' personal involvement and current views on the importance of education could colour their reflections, others expressed their concerns at the time. A series of Otago University public health dissertations that surveyed diabetes patients about their education and knowledge of their condition illustrate such concerns. After conducting a similar patient survey to the one mentioned above, a student in 1964 noted that patients needed not only education about practical details of disease management, but also required

⁷ Dr Bob Smith, Personal Communication, 3 June 2011. Admission for education in testing urine, injecting insulin and diet planning was typical in the 1950s and 1960s in Britain also. Non-insulin requiring patients typically attended clinics on a weekly or fortnightly basis for dietary instruction in Britain: see Moore, pp.145–6.

⁸ Pat Carlton, Interviewed by C.E. Harper, 31 August 2011.

⁹ Lee Brehaut (nee McLeod), Interviewed by C.E. Harper, 4 July 2011.

¹⁰ Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

explanations about why, for instance, dieting was necessary. In his view, it was ‘the duty of the medical profession to sufficiently educate the diabetic ... so that he may make an informed choice [whether to follow advice]. The diabetics in the series did not make such a choice.’¹¹ A 1970 survey of elderly patients found that while most had confidence in their general practitioners, ‘several thought that their doctors were not listening adequately or taking notice of the patient’s feelings’.¹² Most of the survey participants had ‘scanty’ knowledge of the disease, many were fearful about going out and relied heavily on relatives, suggesting to the author a need for greater ‘responsibility of doctor, hospital and community’.¹³ A 1972 investigation, which largely attributed educational efficacy to a patient’s ‘personality’ and whether they had a ‘co-operative and imaginative wife’, nevertheless indicated that, ‘if a diabetic does not have the gumption to find a good doctor, then he is badly handicapped’.¹⁴ Concerns about patient education were also concerns about professional education.

Contemporary doctors desired to know more about diabetes. The Medical Advisory Panel of the Diabetic Association of New Zealand (DANZ) and University of Otago Department of Preventive and Social Medicine surveyed doctors about their diabetes education needs in the early 1970s. This survey revealed that many doctors lacked confidence in handling ‘unstable diabetics’ (patients with variable insulin requirements). In particular, sixty-three out of seventy-eight general practitioners felt they were inadequately equipped to deal with these patients.¹⁵ The survey found 90 per cent of doctors had referred diabetes patients to outpatient clinics, which led the Panel to suggest these needed further development as educational

¹¹ ‘Some medical and social aspects of diabetes’, Preventive Medicine Dissertation, University of Otago, 1964, pp.38–39.

¹² ‘Diabetes in the later years’, Preventive Medicine Dissertation, University of Otago, 1970, p.53.

¹³ *Ibid.*, pp.57–58, 63. Another study of mostly older patients who had gone blind from diabetes, according to the author, had less of these sorts of problems; some even kept abreast of the latest therapeutic research. Most of the patients in this series, however, had close family support and help from the Royal New Zealand Foundation from the Blind: ‘Diabetes and blindness’, Preventive Medicine Dissertation, University of Otago, 1974.

¹⁴ ‘Living with diabetes’, Preventive Medicine Dissertation, University of Otago, 1972, pp.40–42.

¹⁵ D.W. Beaven, J.S. Dodge, J.A. Kilpatrick and G.F. Spears, ‘Education and diabetes: attitudes, opinions and needs of New Zealand doctors’, *New Zealand Medical Journal* (NZMJ), 81, 533, 12 February 1975, p.98.

facilities.¹⁶ The Panel considered it was ‘disturbing’ that many doctors allowed some degree of sugar in urine (a practice used to prevent hypoglycaemia in patients on insulin), only a third were monitoring blood sugars and most did not see their patients enough.¹⁷ Only 32 per cent recognised that diabetes was a major cause of blindness in New Zealand and few had ever referred patients to ophthalmologists.¹⁸ While many doctors wanted ongoing postgraduate training in diabetes, they faced financial and organisational difficulties, such as arranging cover, and the majority suggested if day courses were near to their hometown they would more readily attend.¹⁹

By the early 1970s, many medical professionals and patients were becoming concerned about their lack of knowledge about diabetes and believed more education could enhance their abilities to manage the disorder more effectively. Subsequently, those in diabetes services began to think critically about who should provide education, how and where.

‘It is essential that a Diabetes Sister be appointed’

In 1968–1969, Dr Donald Beaven, Director of the Medical Unit at Princess Margaret Hospital and head of Diabetes Services in Christchurch, went on sabbatical in order to take up an invited professorship at the University of Geneva in Switzerland. During his time away from New Zealand, Beaven visited university health centres and various hospitals in Europe and North America to observe the operation of their diabetes services. On his return to Christchurch, Beaven reported to the North Canterbury Hospital Board (NCHB) that it was

¹⁶ Ibid., p.97.

¹⁷ Ibid.

¹⁸ Ibid., p.98.

¹⁹ Ibid., p.99. The challenges, and necessity, for continuing education for general practitioners in all areas was an important issue in the 1970s with rapid developments in treatments, epidemiology, and also demographic and social changes: see Dr Rae West, ‘The Education of the General Practitioner, Continuing’, in J.G. Richards, ed., *The General Practitioner in New Zealand*, Auckland, 1978, pp.36–41.

essential, in my opinion, that a Diabetes Sister be appointed. Such a qualified nurse at other centres assists in the outpatient clinics, tours the wards daily to contact all sisters regarding diabetics. It is customary for her to supervise patient training and education ... [and keep] a central record of all diabetics passing through the hospital or its clinics.²⁰

Beaven's recommendation was adopted and had long-reaching consequences: the appointment of a diabetes sister occasioned a reorganisation of the Christchurch Diabetes Clinic, a new approach to diabetes education and a challenge to hospital hierarchies.

Beaven, like many diabetes specialists in Western countries, believed hospital diabetes services had to adopt a greater focus on ambulatory care and patient education to improve health outcomes and free up hospital resources. In particular, specialists deemed the hospitalisation of newly diagnosed diabetes patients, and overloaded outpatient clinics clogged with chronic patients, as an ineffective and inefficient use of resources.²¹ These practices were costly and – many believed – not in the best interests of their patients, who were placed in a dependant and unnatural environment. The extraordinary environs, doctors felt, limited learning about the condition (since the patients were forced into a passive role), and made it challenging for the doctor and patient to determine insulin requirements during normal, daily activity. Specialists may have also had less altruistic motives for challenging the status quo. Martin Moore suggested in his thesis that British hospital consultants also desired to offload unexciting aspects of routine diabetes care down the medical hierarchy.²² In any case, reports in medical journals provided a persuasive impetus for change. The introduction of outpatient education programmes and clinic reorganisation in the United States in the late

²⁰ D.W. Beaven 'Diabetes Services and Research', November 1969, D.W. Beaven Papers, Accession #195, 36867, Macmillan Brown Library, Christchurch (MBL).

²¹ Director of the British the Medical Research Council's Epidemiology Unit, Archie Cochrane, was one of the most famous non-diabetes specialists to point out the inefficiencies of diabetes outpatient clinics: A.L. Cochrane, *Effectiveness and Efficiency: Random Reflections on Health Services*, London, 1972, p.56.

²² Moore, pp.157–9.

1960s and early 1970s was credited with significant cost savings from reduced hospital admissions, and with patients' improved blood glucose control.²³

In New Zealand, Beaven, who was appointed Professor of Medicine at the Christchurch Clinical School in 1971 and elected to the NCHB in 1974, had developed a strong interest in the academic evaluation, audit and the cost-benefit analysis of patient education and organisation of services. Christchurch Hospital already had a policy not to routinely admit new diabetes patients, while general practitioners were supposed to refer patients to the hospital outpatient clinic only for initial consultations or emergency management issues. Beaven and colleagues, however, found a high rate of frequently-returning patients and increasing numbers of new referrals, which, combined with 'poor productivity of the consulting staff', put the clinic under considerable pressure.²⁴ Beaven and the clinic's supervising nurse, Alison Helm, believed they could address these issues through an education programme which encouraged self-sufficiency, and systems for tracking patient care.

Over 1975, the Christchurch Hospital diabetes outpatient clinic underwent a reorganisation which included a new education programme, patient bio-feedback, and an audit. The Hospital's Management Services developed a plan for the clinic to provide 'a packaged deal

²³ Beaven made an overseas trip to study these programmes in detail in 1975: D.W. Beaven. 'Report on Refresher Leave, May-June 1975', D.W. Beaven Papers, Accession #195, 36721, MBL; D.W. Beaven 'Comments on Diabetes Situation in the United Kingdom', 1975, D.W. Beaven Papers, Accession #195, 36757, MBL. He was particularly impressed with Miller and Goldstein's work in Los Angeles, the Spauldings' in Canada, Davidson's in Alabama, and Etwiler's in Minneapolis: see L.V. Miller and J. Goldstein, 'More efficient care of diabetic patients in a county hospital setting', *New England Journal of Medicine*, 286, 26, 29 June 1972, pp.1388-91; R. Spaulding and W.B. Spaulding, 'The diabetic day care clinic', *Journal of the Canadian Medical Association*, 114, 1976, pp.780-3; J.K. Davidson, 'Educating diabetic patients about diet therapy', *Bulletin of the International Diabetes Federation*, 2, 1975, pp.3-7; D.D. Etwiler and J.R. Rob, 'Evaluation of programmed education among juvenile diabetics and their families', *Diabetes*, 21, 9, September 1972, pp.967-71.

²⁴ D.W. Beaven, Alison Helm, J.A. Stafford and A.D. Hunter, 'Patient self-sufficiency: re-organisation of a diabetes clinic', *NZMJ*, 88, 620, 22 September 1978, p.251.

for the education of new diabetics'.²⁵ In a series of meetings with hospital staff and publicity to general practitioners, Beaven and Helm emphasised the educational objectives and reiterated the new, purely consultative, function of the clinic. The clinic agreed, however, that it would annually review 'unstable patients', particularly if they were young and required large amounts of insulin. Helm was responsible for advising all ward nurses on diabetes education, as well as education in outpatient services. The patient educational programme consisted of four sixty to ninety minute classes over four weeks.²⁶ Patients answered self-administered questionnaires to help Helm assess their knowledge of diabetes and evaluate the programme.²⁷ She also managed a register which was designed to measure the effectiveness of the programme, and any subsequent complications developed by patients. Patients now had access to their own blood glucose test results (the laboratory technicians would now explain the significance of these to the patients), which were recorded on a card they carried between laboratory and doctor's visits.²⁸ An audit at the end of 1976 found that the percentage of new patients who returned within twelve months had fallen from 60 per cent in 1974 to 35 per cent, and that there had been a statistically significant decrease in the weights of adult-onset patients over previous years.²⁹ Following this, in 1976, the NCHB officially appointed Helm as New Zealand's first diabetes educator. The role included working with nurses and dietitians in the wards of all hospitals in the Canterbury region and continued responsibility for the diabetes clinic teaching programme.³⁰

²⁵ *Ibid.*, p.252.

²⁶ *Ibid.*

²⁷ Alison Helm and J. Stafford, 'The Christchurch Hospital diabetes educational programme', *NZMJ*, 87, 603, 11 January 1978, p.16.

²⁸ Beaven, Helm, Stafford and Hunter, p.251.

²⁹ *Ibid.*, p.252.

³⁰ Minutes of Meeting of Executive of the DANZ, 4 September 1978, p.1, Diabetes New Zealand, Wellington (DNZ).

Helm wrote or co-authored several articles in medical and nursing journals that emphasised the specialist skills of the diabetes nurse educator and the value of the new educational approach. Referring doctors, she argued, often lacked the time to spend teaching people with diabetes and their families — she suggested patients needed ten hours of education, at a ‘conservative estimate’, in order to understand and adequately manage the condition.³¹ Helm described her process: she contacted the patient to assess his or her needs and abilities, and then began ‘to MOTIVATE the Diabetics and their families to realise the vital necessity to learn about their own diabetes’; her use of capital letters emphasised motivation as the critical outcome of diabetes education.³² She accompanied patients on their clinic visit with the specialist consultant or registrar and dietitian and then registered the patients in the educational programme.³³ Teaching took place in a large seminar room that could accommodate thirty people, which was located in the new medical school, across the road from the outpatient clinic. Helm created an ‘informal classroom atmosphere’ in which she utilised various learning techniques, such as videos, demonstrations, hand-outs and discussion groups. Dietitians and doctors ran some of the lessons.³⁴ At the end of each session, patients could privately discuss personal problems and, if needed, Helm could arrange appointments with the Christchurch Diabetic Society Field Officer (a social worker), Doreen Hill.³⁵ Helm encouraged the patients’ family and friends to attend the programme.

The novelty of Helm’s position caused tensions within the hospital. On his return from Geneva, Beaven had wanted the NCHB to appoint a diabetes nurse educator in 1970, but he felt that there was nobody with suitable experience (Helm was only appointed as supervising

³¹ Helm p.30.

³² Ibid.

³³ Helm and Stafford, p.15.

³⁴ D.W. Beaven, R.S. Scott, A.M. Helm, M.J. Clarkson, J.M. Bremer, M. Price, L.K. Taylor and J.M. Stafford, ‘Regional diabetes education centres: a unique New Zealand consumer–health services project’, *IDF Bulletin*, June 1983, p.2. The quote is from Helm, p.30.

³⁵ Helm and Stafford, p.15.

nurse that year). Additionally, Beaven had recommended that the nurse educator should have joint accountability to the Physician in Charge of Diabetes Services (himself) and the Chief Nurse.³⁶ When officially appointed, in 1976, Helm had considerable autonomy from traditional hospital nursing hierarchies. Some hospital staff questioned who she was accountable to, as she worked across wards, and between the clinic and hospitals. At a medical conference in 1977, a Wellington physician who was interested in promoting more nurse educator positions succinctly framed the issue Helm encountered: the ‘concept that nurses are able to make ideal diabetic educators is not readily accepted by nursing administrators’.³⁷ Professional resistance to diabetes nurse educators was not unique to New Zealand; such appointments overseas generated similar problems with the reorganisation of job descriptions and boundaries.³⁸ These issues would be further exacerbated in New Zealand with plans in train for Helm to begin operating outside hospital spaces.

‘The marriage between the voluntary organisation and the health professionals’

In the late 1980s, the President of the Christchurch Diabetes Society, John Patterson, wrote an article in the Society’s newsletter which reflected on the development of the country’s first community-based educational facility, the Christchurch Diabetes Centre. Patterson noted that Beaven had first suggested such a facility to the Society in 1972, so when a suitable building became available five years later, ‘Don Beaven’s gamble in asking the Society to get it started had paid off. The Diabetes Centre provided the final seal on the marriage between the voluntary organisation and the health professionals.’³⁹ From Patterson’s perspective, ‘It has been unique for diabetes that the voluntary organisation worked on equal terms with the

³⁶ Beaven et al, ‘Regional diabetes education centre’, p.2.

³⁷ R.B.W. Smith, ‘Why educate the diabetic?’, NZMJ, 86, 596, 28 September 1977, p.277.

³⁸ F.I.R. Martin, *A History of Diabetes in Australia*, Melbourne, 1998, p.107.

³⁹ John Patterson, ‘Don Beaven – the Centre and the Society’, p.11, D.W. Beaven Papers, Accession #195, 36813, MBL. Beaven had copied the article, originally from the Christchurch Diabetes Society magazine, and would have been from the late 1980s based on information about the upcoming integration of the centre with outpatient services at a new venue.

medical people'. He quoted Helm's belief that, 'The scheme was well ahead of its time and it is interesting to see the Board's changing attitude today towards voluntary societies working in the community.'⁴⁰ Consumer organisations would provide a critical impetus for establishing a new approach to diabetes education in New Zealand.

Funded and managed in part by the diabetes society, the Diabetes Centre was an unusual service arrangement for the NCHB. In 1975, Beaven had proposed that the NCHB should rent an old house near the hospital for a diabetes teaching centre for the outpatient's education programme and 'round-the clock' advice. Nowhere suitable was vacant so they began using a medical school seminar room.⁴¹ Beaven claimed the Board's medical administration 'were enthusiastic about the concept' as it would reduce pressure on hospital facilities. Funding, however, was not forthcoming; sitting between primary and secondary care, the NCHB believed it could not use funds designated for hospital purposes. In order to provide sufficient funds for the new centre, Beaven approached major overseas trusts with proposals to develop the centre further as a training site for health professionals from across the South Pacific.⁴² These approaches were also unsuccessful. In late 1977, Helm heard that rooms in the new Christchurch Arts Centre were available for community groups to rent and she rang Beaven, who contacted the Christchurch Diabetes Society.⁴³ The Society, which had wanted to set up its own drop-in centre for over a decade, offered to pay the first year's rental, provide the services of its social worker and \$5,000 for fittings and furnishings.⁴⁴ The Board accepted this offer and Society volunteers began renovations. Hospital staff already undertaking the

⁴⁰ Ibid., p.12.

⁴¹ Ibid. The 'round-the-clock' service probably referred to a nurse operated telephone advice line as Beaven had observed in California.

⁴² D.W. Beaven, 'History of Development and Funding of the Diabetes Centre', June 1988, D.W. Beaven Papers, Accession #195, 36808, MBL

⁴³ Patterson, p.11.

⁴⁴ Harris to Beaven, 2 November 1977, CAVX 2912 CH588 Box101/ 14/47 (9289), Archives New Zealand, Christchurch (ANZC). Later, the Society also funded a half time secretary, diabetes educator and research officer.

outpatient educational programme would work at the Diabetes Centre as well as a research officer. Beaven believed this was ‘an exciting venture with great advantages accruing to the Hospital Board’ through the promotion of community care.⁴⁵

The Board’s promotion of community care was important as New Zealand, like elsewhere, experienced gathering political and professional support for the concept. In the 1970s, bodies of health care workers, officials and consumers pushed for the re-orientation of the health system towards community-based services and deinstitutionalisation, most notably for mental health services.⁴⁶ According to Moore, a select few British general practitioners began to encourage their colleagues to take greater responsibility in diabetes management by utilising a ‘newly resurgent ideology’ of general practice at this time; their ‘rhetorical strategies’ emphasised the familiarity, and personalised continuity of care offered in community practice.⁴⁷ In New Zealand, driven by recent graduates, and the Royal New Zealand College of General Practitioners, general practitioners fashioned themselves as specialists in community health, engaging in more preventive medicine (such as screening) and research, and creating guidelines for standards of care just like other medical specialisations.⁴⁸

At a governmental level, there were new initiatives to promote community care which crossed party lines. Both the second National government (1960–72) and third Labour government (1972–75) introduced and expanded schemes for general practitioners to hire subsidised

⁴⁵ D.W. Beaven, ‘Interim draft report for the Management Committee on the relationship between the Diabetes Centre and the North Canterbury Hospital Board’, 24 January 1978, Diabetes – including special surveys, 1965–81, CAVX 2912 CH588 Box101/ 14/47 (9289), ANZC.

⁴⁶ Brown, ‘Organizational Influences’, p.214; Warwick Brunton, ‘Mental Health: the Case of Deinstitutionalization’, in Peter Davis and Toni Ashton, eds, *Health and Public Policy in New Zealand*, Auckland, 2001, pp.181–200; Kate Prebble, ‘Ordinary Men and Uncommon Women: a History of Psychiatric Nursing in New Zealand Public Mental Hospitals, 1939–1972’, PhD thesis, University of Auckland, 2007, pp.230–1. This was also part of the primary health care movement: see Chapter Seven.

⁴⁷ Moore, pp.160–6.

⁴⁸ Richards, *passim*; S.R. West, Royal New Zealand College of General Practitioners, *Manual of Practice Organisation*, Christchurch, 1977.

practice nurses and for hospital boards to set up multidisciplinary primary care health centres in the early 1970s.⁴⁹ Labour's 1974 White Paper on Health proposed replacing hospital boards with area health boards to better integrate the administration of public health, primary and secondary care. Stakeholders critiqued other aspects of the paper and it, like the government, was defeated in the election of the following year.⁵⁰ However, the new National government continued investigating administrative reform and ways to address rising health expenditure, the vast majority of which went towards hospitals.⁵¹ In 1977, Health Minister Frank Gill introduced a new funding stream for community health projects, derived from a tax on beer and tobacco. Hospital boards could apply to this fund via the Health Department for projects that were likely to reduce hospital bed usage and promote good health, disease prevention and rehabilitation in the community.⁵²

In Beaven's words, the Christchurch Diabetes Centre appeared 'tailor made' for such funding.⁵³ From the mid-1970s, community-based diabetes centres of various forms were set up in Australia, the United States and some European countries.⁵⁴ Dr Paul Moffitt, a diabetes physician at the Royal Newcastle Hospital in New South Wales, was responsible for one such centre, which became widely cited in the medical literature. In 1975, Moffitt persuaded his hospital board to purchase a shop, away from the hospital grounds, and convert it into an education and stabilisation day unit. He projected it would reduce expenditure on

⁴⁹ 'Editorial: Health Centres', NZMJ, 79, 500, 10 October 1973, pp.307–8; Wellington Research Committee of the Wellington Faculty, Royal New Zealand College of General Practitioners, *A Survey of the Fully Subsidised General Practice Nurse in New Zealand*, Wellington, 1983, p.1.

⁵⁰ For analysis of the opposition to the White Paper, see Derek Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Health*, Wellington, 1995, pp.214–7; and Linda Bryder, *A Voice for Mothers: The Plunket Society and Infant Welfare, 1907–2000*, Auckland, 2003, pp.174–8.

⁵¹ *Ibid.*, pp.217–20; Hon. George Gair, 'Managing Change as a Minister of the Crown', MA Thesis, Auckland University of Technology, 2010, pp.83–85.

⁵² South Island Correspondents, 'The state of the health service: community health projects in New Zealand', *Community Health Studies*, 4, 2, 1980, p.135.

⁵³ Beaven, 'History of Development and Funding of the Diabetes Centre', p.2.

⁵⁴ These did not appear in Britain until the 1980s: see Valier and Bivins; and J.L. Day and M. Spathis, 'District Diabetes Centres in the United Kingdom', *Diabetic Medicine*, 5, 4, pp.372–80.

hospitalisations. Moffitt came to speak at a New Zealand diabetes conference in June 1977, following which Beaven submitted an application for a community care grant to the Health Department on behalf of the NCHB. Beaven's application made the point that Moffitt's centre had saved over 800 bed day stays in hospital and approximately \$80,000–90,000 in its first year of operation.⁵⁵ Having the same objective to reduce hospitalisation, the Christchurch Centre would offer a community-based multidisciplinary teaching team including a diabetes nurse educator, dietitians, social worker, district nurse, specialist physician and podiatrist. The Health Department, however, declined the application because it believed the Christchurch Centre would be similar to a traditional diabetes outpatient clinic and was thus the responsibility of the NCHB. In response, the Interim Management Committee for the Diabetes Centre decided to press the Medical Superintendent-in-Chief to make their case: they hoped to get the Department to reconsider while going ahead with the Arts Centre tenancy. The Diabetes Society's involvement seems to have been critical to a successful grant reapplication in January 1978: the new application emphasised the Centre as 'a true community project'.⁵⁶ The Centre received three years funding for the part salaries of staff, rental, heating, lighting and cleaning.

Moving diabetes education into the community in this way took time, held up by the need to convince some health professionals and administrators who were used to traditional hospital boundaries. Contemporary analysis of the new community health funding scheme noted that 'a major problem faced by all the projects [was] trying to function effectively under a hospital administration ... not prepared, either philosophically or organizationally, to deal with the

⁵⁵ NCHB, 'Application from Christchurch for Community-Based Diabetes Resource Centre', 13 July 1977, p.2, D.W. Beaven Papers, Accession #195, 36808, MBL. The Christchurch Centre did not include stabilisation facilities; these remained with the diabetes outpatient clinic.

⁵⁶ A copy of the application is available in Community Care – Diabetes Centre, 1978–80, CAWU 2985 CH701 Box 45/ 5/31/7, ANZC. The Arts Centre Trust Board had also agreed to provide a reduced rent.

community health initiative'.⁵⁷ In the Diabetes Centre's case, personal animosities made the transition more difficult. In October 1978 Helm's husband, Bert, wrote to Beaven concerned that Christchurch Hospital's Medical Superintendent Dr Ross Fairgray had a 'personal vendetta' against his wife. Fairgray had accused Helm of not doing her job on the hospital wards, which, according to Bert, who knew the extra hours she put into counselling patients, was simply not true.⁵⁸ Beaven assured Bert that he knew of Helm's deep commitment to her work and that Fairgray was more interested in 'his own personal authority' than patient services.⁵⁹ Beaven believed Fairgray did not see the value of the Centre or recognise that it was the Board's responsibility.⁶⁰ Beaven went straight to the NCHB's Superintendent-in-Chief, Lynton McHardie Berry, to ascertain why he had not transferred Helm to a permanent base at the Centre, which had been due to occur several months earlier. The delay was caused by anxiety among the nursing hierarchy, who did not want Helm 'lost from the hospital and into the community': they wanted assurances she would still be available on the wards.⁶¹ Berry authorised her to move to the Centre immediately. Fairgray wrote a lengthy letter to Beaven which stated his displeasure that, 'it appears that you have gone over the heads of the Superintendent of the Christchurch Hospital, the Principal Nurse and Chief Nurse Officer'.⁶² In January 1979, Berry arranged for the Chief Nurse and Beaven to meet to 'come to some amicable understanding' and 'bring this whole unpleasant matter back into focus'.⁶³

⁵⁷ 'The state of the health service', p.136.

⁵⁸ Helm to Beaven, 24 October 1978, D.W. Beaven Papers, Accession #195, 36706, MBL.

⁵⁹ Beaven to Helm, 8 November 1978, D.W. Beaven Papers, Accession #195, 36706, MBL.

⁶⁰ There had been previous heated exchanges between the two over the Christchurch Diabetes Society's social worker having access to hospital wards: see Beaven to L.M. Berry, c. February 1977; Berry to Beaven, 21 February 1977, D.W. Beaven Papers, Accession #195, 36794, MBL.

⁶¹ Beaven to Alison Helm, 18 December 1978, Community Care – Diabetes Centre, 1978–80, CAWU 2985 CH701 Box 45/ 5/31/7, ANZC.

⁶² Fairgray to Beaven, 21 December 1978, D.W. Beaven Papers, Accession #195, 36758, MBL.

⁶³ Berry to D.A. Andrews, 16 January 1979, D.W. Beaven Papers, Accession #195, 36758, MBL. Margaret Jamieson, the first diabetes nurse educator in Nelson, outlined a very similar account of the tensions with the nursing administration in her appointment and accountability to medical officers: Margaret Jamieson, *History of Diabetes Nelson Incorporated: Formerly, The Diabetic Association of New Zealand (Nelson Division), 1957–2005*, Nelson, 2005, pp.129–32.

Part of the nursing hierarchy's discomfort with Helm's new position was with the dissolution of clear lines of authority, which uniforms made obvious in the hospital setting but were antithetical to the new educational approach promoted at the Centre. Beaven asked Helm not to wear a uniform at the Centre, which according to his later recollections, prompted a Principal Nurse (presumably the one mentioned above) to threaten her resignation. Beaven explained many years later that non-uniformed nurses were an essential part of the Centre's philosophy: 'people with diabetes shouldn't be subjected to uniforms outside the hospital – we were trying to help them live a normal life'.⁶⁴ Other community-based nurses, such as Plunket nurses, were also uniform-free by the mid-1980s.⁶⁵ The Centre tried to minimise the divisions between patients and professionals, as its dietitian Madeleine Price explained in a 1982 journal article: 'white coats and uniforms are inappropriate as these can foster a formal and potentially threatening atmosphere'.⁶⁶ For similar reasons, the Centre staff deliberately used the terminology of 'consumers' or 'clients', as opposed to 'patients', when communicating with general practitioners, to further emphasise a less hierarchical relationship.⁶⁷

Initially, many general practitioners were wary of the Centre, as they considered that it was an example of the hospital encroaching on their services. At a 1979 Centre Management Committee meeting the Committee's representative of the Royal College of General Practitioners reported that the College 'think the general practitioners may lose patients, being unsure of the Diabetes Centre's true educational, not treatment value'.⁶⁸ The Centre operated on a referral system – either from hospitals, the diabetes clinic or general practitioners. In

⁶⁴ Bee Dawson, *Dedicated to Diabetes: Diabetes New Zealand, 1962–2002*, Wellington, 2002, p.25.

⁶⁵ Bryder, p.232.

⁶⁶ Madeleine Price, 'The role of the dietitian in a multi-disciplinary team', *Journal of the N.Z. Dietetic Association*, 36, 2, October 1982, p.22.

⁶⁷ Beaven et al, 'Regional diabetes education centre', p.4.

⁶⁸ Minutes of the Management Committee of the Diabetes Centre, 27 March 1979, Diabetes & Management Committee 1, 1977–84, CAWU 3584 CH853 105/d O41, ANZC.

1980, the second full year of operation, only 30 per cent of general practitioners referred their newly diagnosed patients to the Centre.⁶⁹ This improved as the Centre publicised its guidelines, among which was the directive that staff would not change a patient's treatment regime.

It may have also helped that Beaven had a good relationship with many local doctors through his work at health centres, helping them develop educational resources and audit procedures; Beaven claimed in 1983 that, 'The Centre sees every practitioner as an extension of the Centre.'⁷⁰ Dr Russell Scott, a specialist who joined the Centre in the early 1980s, explained in the *Star*: 'The aim was to educate general practitioners and their patients in new treatments and to encourage them to adopt more aggressive and independent roles in handling the disease.'⁷¹ By this time, more than half of the region's general practitioners had attended annual one-day sessions at the Centre, and in 1982, 85 per cent of general practitioners referred their new patients.⁷² Additionally, the Centre held courses for district and practice nurses, medical and nursing students and lay administrators. The Centre's educational programmes tried to re-orient both people with diabetes, and health professionals thinking about the condition.

This re-orientation was research-based. Staff recorded each phone call, walk-in and appointment, and compiled statistics that they presented to the Management Committee's monthly meetings. A working party also met once a month to assess evaluation and

⁶⁹ Beaven et al, *Regional diabetes education centre*, p.4

⁷⁰ Mary Hay, S.J. Carson and D.W. Beaven, 'A trial audit to assess the adequacy of diabetes mellitus management in general practice', *NZMJ*, 89, 638, 27 June 1979, pp.482-4; D.W. Beaven *Curriculum Vitae*, c.1984, D.W. Beaven Papers, Accession #195, 36823, MBL; 'Review of Community Health Care Programmes – Christchurch Diabetes Centre', *Community Care – Diabetes Centre, 1981-83*, CAWU 2985 CH701 Box 45/5/31/7, ANZC.

⁷¹ 'Diabetes Centre struggles for life', *Star*, 28 October 1981.

⁷² Beaven et al, *Regional diabetes education centre*, p.4

operational processes. Some evaluation research included measuring clients' anxiety before and after attendance, and glucose control both through urinary testing and the new HbA1C test.⁷³ The HbA1C test gave a measure of average blood sugar over the previous one to three months providing a more systematic method for doctors to assess long-term control.

Additionally, self-blood glucose monitoring was becoming a realistic alternative to urine testing as simple finger-pricking devices and portable meters came on the international market in the late 1970s.⁷⁴ The Centre purchased fourteen meters, which it loaned to clients, and engaged a medical student to undertake an evaluation of home blood glucose monitoring in 1979. This research showed technology alone was not enough to improve glucose control. The team at the Centre found pregnant women, with the additional motivation of their baby's well-being, had better results. They concluded that while patients could 'technically perform [self-measurement] reasonably well' it was 'only through further education and regular health professional support' that patients gained the confidence to adjust their own treatment.⁷⁵ Such findings were in concert with the contemporary overseas research that posited better control resulting from home blood glucose monitoring could be attributable to the increased communication between health professional and patient.⁷⁶

At the Centre, professionals aimed to take a complete view of the person with diabetes and recognised the contribution they made to the management approach. Price made this point in

⁷³ D.W. Beaven, 'Summary of the Assessment & Evaluation of Diabetes Mellitus: A Project Funded in the Diabetes Centre by a Community Health Care Grant', May 1980, CAWU 3584 CH853 105/d O41, ANZC.

⁷⁴ Martin, p.67; Aaron Mauck, 'Managing Care: The History of Diabetes Management in Twentieth Century America', PhD dissertation, Harvard University, 2010, p.343.

⁷⁵ Beaven et al, 'Regional diabetes education centres', p.6. The Diabetes Centre Team produced several research papers on the subject: R. Cox, D.W. Beaven and A.W. Helm, 'Home monitoring of blood glucose – a retrospective assessment in 38 insulin requiring patients', NZMJ, 92, 667, 10 September 1980, pp.193–6; R. Cox, R.S. Scott, A.B. MacLean and D.W. Beaven, 'Home monitoring of blood glucose in diabetic pregnancy', NZMJ, 94, 696, 25 November 1981, pp.371–3; R.S. Scott, 'Home blood glucose monitoring – an evaluation of the BM test glycaemia 20-800 system', NZMJ, 93, 684, 27 May 1981, pp.340–1; V.M. Mountier, R.S. Scott and D.W. Beaven, 'Use and abuse of home glucose monitors', *Diabetes Care*, 5, 5, September 1982, pp.542–4; R.S. Scott and D.W. Beaven, 'Self-measurement of blood glucose', NZMJ, 95, 719, 10 November 1982, pp.772–3.

⁷⁶ This point was emphasised by Professor K.G.M.M. Alberti of the University of Newcastle on Tyne when he spoke at the triennial course in diabetes in Wellington in 1980: *Newsletter of the NZSSD*, 12, October 1980, p.3.

the *Journal of the N.Z. Dietetic Association*: ‘Recognising and meeting the needs of the diabetic as a real and whole person, communicating with genuine interest and concern can help motivate the diabetic to make desirable behavioural changes.’⁷⁷ While health professionals were deciding what was desirable, this should not be understood as ‘medical imperialism’. To see it that way denies the agency that people with diabetes had in developing the Centre and its approach.

The Centre was a base for the Diabetes Society, predominantly made up of people with diabetes, many of whom provided voluntary services. The society offered a library, afternoon craft classes and peer support groups. Members of the public could drop in to ask questions and pick up pamphlets. Monthly meetings of special consumer groups such as parents, youth and pregnant women, were opportunities for the perspectives of these cohorts to be included in the operation of the Centre. Society members even taught in courses for health professionals and medical students.⁷⁸ The Centre’s Management Committee included two elected representatives from the Diabetes Society, which gave consumers the ability to participate in decision-making alongside diabetes professionals, general practitioners and medical administrators. This participation should be mediated by an awareness of the greater power that the NCHB wielded as the major funder of the Centre after the community health grant ran out.⁷⁹ Nevertheless, consumer representation was something the Society fought for, and maintained, throughout the 1980s, despite funding cuts, Board reorganisation, and

⁷⁷ Price, ‘The role of the dietitian in a multi-disciplinary team’, p.23.

⁷⁸ Beaven et al, ‘Regional diabetes education centres’, p.4.

⁷⁹ Laurie J. Brown, ‘Utilisation of a Community Based Health Service: A Study of the Christchurch Diabetes Centre’, MA Thesis, University of Canterbury, 1981, p.45. The community health grant scheme was short-lived. In 1983 the extra funding was incorporated into boards’ block funding grants, which meant community services now came under the jurisdiction of local boards and their priorities. Over the 1980s, the development of community care was piecemeal and, at a time of fiscal pressure, hospital expenditure was prioritised: see Brown, ‘Organizational influences’, p.216.

rationalisation of hospital and community-based services.⁸⁰ This evidence suggests that those people with diabetes involved in consumer groups, whether co-opted or not, appreciated the philosophy of self-sufficiency—and professionals did not view them as a collection of bio-signs.

Similarly, in Auckland, the local diabetes society was particularly proactive in the establishment of the Auckland Diabetes Community Centre. Auckland Diabetic Society Secretary John Nesfield first proposed that the Society should establish a centre in the mid-1960s, which he envisaged offering residential education courses similar to the pioneering patient education programmes at the Joslin Clinic in Boston. Nesfield had visited the Joslin clinic in 1964. He located a suitable venue, but could not obtain medical support.⁸¹

Nevertheless, Nesfield continued to promote schemes for better education, including having the Society donate \$4,000 to make a video and to purchase audio-visual equipment for a new educational programme at the Auckland Hospital Diabetic Clinic in 1976.⁸² Around this time, one of the clinic's specialists, Dr David Scott, who also served as the Society's Medical Advisor, proposed the establishment of an Auckland centre inspired by Moffit's New South Wales facility. The Auckland Hospital Board approved of the proposal in 1978 and accorded it priority under the community health grants scheme. However, with increasing budgetary constraints, it redirected and scaled back its priorities.⁸³ The Diabetic Society bypassed the Board and approached the Minister of Health, George Gair, in 1980, to urge the Health Department to consider the proposal. This lobbying effectively achieved an annual salary

⁸⁰ Numerous examples are available in the Centre's Management Committee minutes and correspondence files at ANZC. The Centre and diabetes clinic relocated to Princess Margaret Hospital buildings in 1989, following a decision to integrate the region's diabetes services in line with Area Health Board policy and broader trends in diabetes management. The Centre, however, remained a 'joint venture' with the Diabetes Society.

⁸¹ 'Synopsis of the establishment and projected function of the Auckland Diabetes Community Centre', 5 July 1983, Diseases – Diabetes, 1981–84 ABQU 632 W4415 267/ 131/20, (56669), Archives New Zealand, Wellington (ANZW).

⁸² Nesfield to Chief Executive Officer, Auckland Hospital Board, 24 November 1976, Medical services – Care of diabetics, 1955–82, ZABV 4638 A1073 198/a 95/1/44 part 1, Archives New Zealand, Auckland (ANZA).

⁸³ 'Synopsis of the establishment and projected function of the Auckland Diabetes Community Centre'.

grant for two full-time nurse educators, a half-time dietitian and half-time secretary, but the Department considered the Board responsible for housing and maintenance. After protracted negotiations with the Board to find and fund a venue, the Society decided to purchase a house near the Auckland Hospital from its trust fund and a \$92,000 bequest it received from one of Scott's former patients. It took out further loans for renovations. Initially, the Society paid one fifth of the Centre's running expenses and the Board the remaining four-fifths.⁸⁴ Gair officially opened the Centre in August 1983.

The Auckland Centre operated in similar fashion to Christchurch with a multidisciplinary team teaching the philosophy of self-sufficiency to people with diabetes and health professionals. Officially, 'a joint enterprise' between the Board's Extramural Hospital and the Diabetic Society, the Centre housed both the Society's facilities and a 'Diabetes Education and Advisory Service'. Diabetes nurse educator Mary Robinson co-ordinated the latter, which involved dietitians and nurses from the Extramural Hospital, doctors from across the Board's hospitals (many on a voluntary basis), podiatrists, and Diabetic Society volunteers. Joy Patterson, Secretary of the Diabetic Society, served as Administrator. The Centre ran three-day courses for patients and their families (these had originated at hospital sites in 1982) and one-to-one counselling sessions. A telephone service provided additional day-to-day advice or support. As demand expanded, and staff identified new needs, the Centre developed specialised courses for those on insulin, Pacific people, and the elderly, created 'topical' evening sessions (a talk on impotence drew in a particularly large audience), and established support groups for adolescents, pregnant women, and the obese.⁸⁵ The Centre became the

⁸⁴ Ibid. There is extensive correspondence and committee meeting minutes about the centre negotiations and funding arrangements in ZABV 4638 A1073 198/a 95/1/44 part 1, and Medical services – Care of diabetics, 1982–86, ZABV 4638 A1073 190/d 95/1/44 part 2, ANZA.

⁸⁵ Auckland Diabetes Education Advisory Service Annual Reports, 1983–89, Personal Collection of Dr Rick Cutfield. Cutfield, diabetes specialist at North Shore Hospital, took over from Dr Scott and Dr Michael Gill as Medical Director of the Centre in 1985.

base of the region's adolescent diabetes services. Reflecting clinical recognition of the mismatch between the 'rebellious' teenage years and control of blood sugars, this service motivated acceptance through social interaction – staff even took this group on a holiday to the United States, and away on weekend trips involving skiing, rafting and sailing.⁸⁶

In terms of professional education, the Centre provided courses for hospital nurses, nursing students, practice nurses, occupational health nurses, public health nurses, fifth year medical students and general practitioners from across the Auckland region. Always underfunded and short on staff, the Centre did not engage in as much research as in Christchurch. However, it did collect extensive statistics to track attendance and referral patterns. Dietitians and nurses also conducted small studies in education and follow-up procedures, which contributed to their growing specialisation in diabetes education.⁸⁷

Thus, the establishment of diabetes community centres in Auckland and Christchurch demonstrated a consensus on patient self-sufficiency amongst consumer groups and health professionals, who were enthusiastic with the possibilities of patient education in the 1970s and 1980s. However, other health professionals and administrators, who were used to traditional boundaries, could perceive threats in the new services, which made their introduction slow. Those health professionals involved in diabetes education could also perceive threats; these perceptions would surface in a debate over who exactly made the best diabetes educator.

⁸⁶ Adolescent clinics were originally held with paediatric services at Princess Mary Hospital but, with space shortages and resistance from patients to being classified as children, the Centre appeared a more appropriate venue. Rick Cutfield had also recently returned from working in an adolescent clinic in the United States and, along with a Diabetes Educator already at the Centre, Cheryl Atherfold, decided to develop the service: Dr Rick Cutfield, Interviewed by C.E. Harper, 1 August 2011 and correspondence from his personal collection. Dr David Scott reflected on the 'rebellious' adolescent extensively in David Scott and Eva Palatasi Brown, *Stories of Life with Diabetes*, Palmerston North, 1989. Nurses identified diabetes in adolescence as a clinical problem in the 1980s: see Mary Ellen O'Connor, *Freed to Care, Proud to Nurse: 100 Years of the New Zealand Nurses Organisation*, Wellington, 2010, p.214.

⁸⁷ Auckland Diabetes Education Advisory Service Annual Reports, 1983–89.

‘Put aside parochialism’: diabetes education and professional politics

Following Alison Helm’s appointment as a ‘Diabetes Educator’ in 1976, colleagues questioned who was qualified for the position. Helm explained to colleagues in the New Zealand Society for the Study of Diabetes (NZSSD) that, ‘Just as the embryo medical specialist requires time to specialise: so does the diabetes teacher require specialised training before practicing her expertise and calling herself a “Diabetes Educator”. She thus called on colleagues to, ‘Put aside parochialism, and strongly support ... [the establishment of] a suitable course of study for diabetes educators.’⁸⁸ Parochialism, in this case, constituted a turf war between nurses and dietitians, as they both pursued professional autonomy and recognition.

Founded in 1976, the NZSSD reflected New Zealand diabetes physicians’ promotion of a greater role for nurses and dietitians in diabetes management. The previous year, the newly appointed head of Diabetes Services at Wellington Hospital, Dr Robert (Bob) Smith, attended a British Diabetic Association (BDA) conference while on a fellowship at King’s College, London. He recalled what he considered a rather backward scenario: Smith had travelled to the conference with his boss, Dr David Pyke, a senior nurse and a dietitian, but on arrival, he and Pyke had to attend papers for the Medical and Scientific Section while the nurse and dietitian attended those for the Professional Services Section.⁸⁹ Smith would use this experience back in New Zealand. The DANZ’s Medical Advisory Panel was reorganising to include better regional representation and maintain input from the New Zealand Dietetic Association, with which it had established a formal relationship in 1972. Smith took the new

⁸⁸ Alison Helm, ‘Letter to the Editor’, *Newsletter of the NZSSD*, 18, June 1982, p.4.

⁸⁹ Dawson, p.95. The BDA’s Medical and Scientific Section had, after heated debate, decided to exclude nurses and ancillary staff when it formed in 1960: see J.G.L. Jackson, ‘The formation of the Medical and Scientific Section of the British Diabetic Association’, *Diabetic Medicine*, 14, 10, October 1997, p.888. The BDA eventually established a multidisciplinary Education Section in 1983: see D.W. Hide, ‘Association of Diabetic Educators – a Significant Mile-stone’, in Arun K. Baksi, David Hide and Gawin Giles, eds, *Diabetes Education*, Chichester, 1984, pp.121–2.

role of Panel Secretary. For some time, scientists and health professionals other than physicians had expressed interest in joining the Panel, and Smith thought it viable to establish a Medical and Scientific Section to DANZ. Yet, unlike the BDA, he believed this should include ‘all interested in the study and delivery of diabetic care and education’.⁹⁰ About twenty people, meeting at Christchurch Diabetes Centre at the end of a postgraduate course on diabetes, agreed with Smith, and formed the NZSSD.⁹¹

By the end of 1977, the NZSSD had fifty-nine members consisting of physicians, dietitians, nurses, and pharmaceutical company representatives, as well as an epidemiologist, ophthalmologist, obstetrician, statistician, academic in social medicine, and diabetes field officer.⁹² In comparison to Britain, the NZSSD’s broad membership reflected the smaller size of the New Zealand diabetes workforce, but also the period of its formation: it was established at a peak of enthusiasm for multidisciplinary teamwork in health care. The NZSSD’s objectives were to promote diabetes research, education and care by organising courses and meetings, and setting standards for clinics, professionals and patient education.⁹³ It thus provided a forum for developing and debating the new role of diabetes educator.

Although only Helm held the official title ‘diabetes educator’, by the end of the 1970s there were increasing numbers of nurses involved in diabetes education, prompting concerns about role definition. Diabetes nurse educators represented part of the nursing profession’s broader push for professional autonomy; tertiary training and post-basic nursing education were shifting nursing away from an exclusively practical profession to a theoretically grounded one. Nursing theory differentiated a nursing model of care, based on community health and

⁹⁰ *Newsletter of the NZSSD*, 31 March 1977, p.1.

⁹¹ Dawson, p.95.

⁹² *Newsletter of the NZSSD*, 30 December 1977, p.1.

⁹³ *Newsletter of the NZSSD*, 31 March 1977, p.1.

premised on patients as social actors, from a medical model, that emphasised biological disease.⁹⁴ The early diabetes nurse educators stressed this concept: ‘the pupil becomes an individual – with a pancreas’, rather than the other way around.⁹⁵ By conducting research and acting as resource people for other health professionals, the nurse educators demonstrated the shifting practice and professional orientation of nursing. Nurses became decision-makers rather than instruction-followers.⁹⁶ In 1979, DANZ’s Medical Panel met with sixteen people involved in diabetes education in New Zealand to discuss issues arising from the new nurse appointments around the country. The meeting pressed for action on determining standards of training, conditions of service, and career prospects.⁹⁷ The New Zealand Nurses Association (NZNA), which was both a professional organisation and trade union, wanted the position of diabetes nurse educator developed at a level to ensure appropriate financial and professional recognition for their specialised function.⁹⁸ With technological developments of self-blood glucose monitoring and in insulin delivery, diabetes nurse educators were acquiring increased clinical skills. A dietitian in attendance, however, ‘questioned why the nursing hierarchy should have control of diabetes education’.⁹⁹ As dietitians had provided diabetes education since the 1940s, for both those who were on insulin and those who were not, some clearly felt aggrieved by the nurses’ apparent intrusion in the field.¹⁰⁰

This tension between dietitians and nurses played out in the NZSSD’s efforts to establish a training course for diabetes educators over the first half of the 1980s. Helm and others had led

⁹⁴ O’Connor, p.177.

⁹⁵ Alison Helm, ‘The Christchurch Diabetes Centre education programme’, *New Zealand Nursing Journal*, 73, 4, April 1980, p.26.

⁹⁶ Cheryl Atherfold, ‘The History of the Diabetes Nurse Specialist Group in New Zealand’, 6 May 1997, Diabetes Nurse Specialists Section files, NZNO.

⁹⁷ Minutes of a Meeting of the Medical Advisory Panel of the DANZ, 9 March 1979, p.1, DNZ.

⁹⁸ *Newsletter of the NZSSD*, 16 March 1979, p.2.

⁹⁹ *Ibid.*

¹⁰⁰ Kate Prebble documents similar tensions in her history of psychiatric nursing in New Zealand, when occupational therapists and social workers began to be employed at mental hospitals at the same time as psychiatric nurses were losing manual responsibilities and establishing a more therapeutic role: Prebble, pp.238–9.

an early attempt to establish a course at Christchurch Polytechnic, but this fell through due to funding difficulties.¹⁰¹ By 1982, Smith, now President of the NZSSD, noted that in addition to funding it was ‘not proving easy to find a formula on which all can agree’. He relayed that the NZSSD Executive wanted its proposed course to have flexible entry criteria for registered nurses, registered dietitians, ‘or other persons, usually allied health professionals with qualifications that may be individually approved’, for instance, social workers.¹⁰² A record of a meeting to consider the course at the end of the 1982 annual conference reveals the extent of disagreement between health professionals. Attendees had concerns about a single course, suggesting that each discipline had different responsibilities and needed to develop different skills to become effective diabetes educators. While recommending planning and co-ordination skills were essential for all, the participants’ key concern appeared to be that ‘Educators should be termed “Diabetes Educators” not “Nurse Educators”’.¹⁰³ Following this, Helm’s aforementioned comments in the NZSSD newsletter urged members to support the NZSSD to get a course up and running.¹⁰⁴

The Health Department did not support the NZSSD’s proposals for diabetes educator training. In response to the NZSSD’s request for official recognition of its proposed multidisciplinary course in 1982, the Director of the Division of Hospitals argued that ‘there are already elements of diabetes education in the training of a range of medical and paramedical practitioners’.¹⁰⁵ For the Department, such a course would force them to decide how to classify graduates for remuneration purposes. Following several appointments of diabetes educators in the ensuing months, a meeting of Departmental officers asserted that ‘nursing

¹⁰¹ Alison Helm, ‘Summary of a meeting of Diabetes Educators’, *Newsletter of the NZSSD*, 15 September 1981, p.8; Dr Bob Smith, Personal Communication, 3 June 2011.

¹⁰² Bob Smith, ‘A note from the President’, *Newsletter of the NZSSD*, 18 June 1982, p.1.

¹⁰³ Madeleine Price, ‘Record of an informal meeting held at the close of the NZSSD annual conference, 29 May 1982’, *Newsletter of the NZSSD*, 18 June 1982, p.6.

¹⁰⁴ Helm, ‘Letter to the Editor’.

¹⁰⁵ A.J. Sinclair to D.W. Beaven, 23 March 1982, ABQU 632 W4415 267/ 131/20, (56669), ANZW.

training provides the most appropriate background for diabetes educators and that a specific formal training programme is neither necessary nor desirable'.¹⁰⁶ The Department surveyed hospital boards about the issue, which resulted in a policy statement that 'most boards accept that the role is best filled by a registered nurse... It is therefore considered appropriate that a nurse engaged in this activity should be employed under the nursing determination (DG21)'.¹⁰⁷ The NZSSD felt that the Department policy ignored the NZSSD's role in setting professional standards and showed ignorance of the multidisciplinary team approach to diabetes education, as it appeared to exclude everyone except nurses.¹⁰⁸ The Department, however, claimed its only concern was with employment issues, not professional standards or training.¹⁰⁹ At a time of increasing politicisation of the nursing profession, the Department appeared also to be making a stand against nurses' assertion of their right to develop as specialists, over and above their core training and roles.¹¹⁰

In the mid-1980s, diabetes nurses set up a Diabetes Nurse Educators Section of the NZNA, which established their new specialist status. The NZNA first introduced special interest sections in the 1970s, which historian Mary O' Connor has argued reflected two things: first, nursing becoming more specialised; and second, the Association's desire to retain membership in a single organisation.¹¹¹ Around thirty diabetes nurses met in Wellington with a representative from the NZNA in 1984. Auckland diabetes nurse educator Cheryl Atherfold has recalled how they 'spent hours on the floor with sheets of paper and marker pens... There

¹⁰⁶ Alan Henderson, Hospitals Administrator, to attendees of meeting 20 October 1982, 26 October 1982, ABQU 632 W4415 267/ 131/20, (56669), ANZW.

¹⁰⁷ Circular Letter (Hospitals) No.1983/3, ABQU 632 W4415 267/ 131/20, (56669), ANZW.

¹⁰⁸ Melva Clarkson, Secretary of the NZSSD, to Director-General of Health, 22 July 1983, ABQU 632 W4415 267/ 131/20, (56669), ANZW.

¹⁰⁹ Director-General of Health to Clarkson, 13 October 1983, ABQU 632 W4415 267/ 131/20, (56669), ANZW.

¹¹⁰ O'Connor documents the 'more political era', beginning in the latter 1970s, of the NZNA and changing relationships with government into the 1980s: O'Connor, pp.155–219.

¹¹¹ *Ibid.*, p.186.

was plenty of energy for discussion'.¹¹² They elected Mary Robinson as chairperson and Angela Thornton as Secretary/Treasurer. A committee of about nine or ten thereafter met regularly to consider professional issues. The group's objectives were to provide support for the new nursing specialty, education and training, a forum for sharing ideas and concerns, and to set standards of practice. Many diabetes nurses were working independently and even those within multidisciplinary teams found they had to make up their own teaching resources, so the Section wanted to establish linkages throughout the country.¹¹³ The NZSSD provided some opportunity for collaboration at its conferences but the tension with dietitians was an obstacle. The Section was able to establish a four-week course at the Wellington Polytechnic School of Nursing and continued work towards a postgraduate qualification and accreditation.¹¹⁴ It also established relationships with pharmaceutical companies to fund patient educational materials and professional training, resulting in an annual Eli Lilly-sponsored study day and an Ames-sponsored award for educators to attend conferences or undertake study.¹¹⁵

The formation of the Diabetes Nurse Educator Section stirred tensions with dietitians in the NZSSD. At the NZSSD annual general meeting in 1986, the new President, endocrinologist Dr Peter Dunn, voiced concern about the 'potential divisiveness developing within the NZSSD with the nurses developing a special interest group'. The minutes record 'some discussion about whether or not the nurse educators were in any way excluding dietitians'.¹¹⁶ The NZSSD decided to support the nurses' interest group but 'help dietitians to achieve similar aims', as Dunn reminded members they had a responsibility to address the professional aspirations of all its 'diabetes educators', and 'it was important to recall that

¹¹² Atherfold.

¹¹³ Pat Carlton, Interviewed by C.E. Harper, 31 August 2011.

¹¹⁴ *Newsletter of NZSSD*, 28 November 1985, p.2.

¹¹⁵ Pat Carlton, Interviewed by C.E. Harper, 31 August 2011; Atherfold; Jamieson, pp.132–3.

¹¹⁶ Minutes of the Annual General Meeting of the NZSSD, 20 May 1986, pp.2–3, Personal collection of Dr Bob Smith.

management of diabetes is a team effort'.¹¹⁷ NZSSD dietitian members arranged for the New Zealand Dietetic Association to investigate the training and position of diabetes educators overseas.¹¹⁸ The Australian Diabetes Educators Association, formed in 1981, was multidisciplinary and was in the process of developing a universal qualification and salary award for educators of any background. Its President, a dietitian, claimed New Zealand would be going against the practice of 'all major Diabetes Educator Associations' should it limit 'its definition of a diabetes educator to include a nurse educator only'.¹¹⁹ This, however, was not exactly the case: in Canada and the United States, the educator organisations promoted multidisciplinary membership, but the actual conditions of employment and training were distinct between disciplines.¹²⁰ By 1988, the Diabetes Nurse Educators in New Zealand had rebranded themselves as Diabetes Nurse Specialists, while the NZSSD 'policy' confirmed 'that an Educator can be Nurse, Podiatrist, Dietitian, etc. '; both registered nurses and registered dietitians could attend the Wellington Polytechnic educator course.¹²¹ The New Zealand Dietetic Association formed a Diabetes Special Interest Group in 1991.¹²²

Throughout the 1980s, debates over the job title 'Diabetes Educator' suggest the importance of professional politics in the patient education movement in New Zealand. Sue Pollard, President of the Dietetic Association in the mid-1980s, has reflected that 'there was a good team spirit' at the Auckland Diabetes Centre where she worked, but elsewhere, 'if there were

¹¹⁷ Ibid., p.2.

¹¹⁸ Minutes of the Executive Committee of the New Zealand Dietetic Association, 21 February 1986, pp.4–5, Executive Committee – Minute Book, 1981–88, MSY-4310, Dietitians New Zealand Records (MS-Group-0537), Alexander Turnbull Library, Wellington (ATL).

¹¹⁹ Edwina Firth, President Australian Diabetes Educator Association to Jenny Wood, Secretary New Zealand Dietetic Association, 10 June 1986, New Zealand Diabetes Association, 1974–88, 97-005-4/16, Dietitians New Zealand Records (MS-Group-0537), ATL.

¹²⁰ Mary Daly to Jenny Wood, 7 August 1986, 97-005-4/16, Dietitians New Zealand Records (MS-Group-0537), ATL.

¹²¹ Minutes of the Annual General Meeting of the NZSSD, 16 May 1988, p.1, Personal Collection of Dr Bob Smith.

¹²² Minutes of the National Executive Committee of the New Zealand Dietetic Association, 22 November 1991, p.5, National Executive Committee – Minute Book, 1988–2000, MSY-6930, Dietitians New Zealand Records (MS-Group-0537), ATL.

patch protectors it would be the nurses'.¹²³ When remembering tensions with dietitians, Pat Carlton, who was the Diabetes Nurse Educator at North Shore Hospital in Auckland and the Secretary of the NZNA Diabetes Nurse Specialist Section in the late 1980s, laughed, 'Oh there always has been!'¹²⁴ She attributed this to nurses stepping into a role that dietitians had always had, but as dietitians did not handle blood products, the advent of blood glucose monitoring necessitated nurse involvement. Technology was only part of the story: concerns about pay, professional status, and the NZSSD's desire to encourage a wide range of health professionals to view education as the primary task of diabetes management were also important to the new role. That nurses became so dominant reflects their greater numbers, the relative power of the NZNA and the wider imperatives within nursing at this time to develop specialised roles they hoped would bring more autonomy, job satisfaction and possibly more pay.

Conclusion

Hospital-based physicians were key instigators of the diabetes education movement, but nurses and dietitians were active agents in developing education as their special area of expertise. As part of this, they built an identity around their ability to see the patient as 'a real and whole person'.¹²⁵ This may have been what Martin Moore called a 'rhetorical strategy' to claim greater authority within the diabetes management team, and diabetes physicians may also have been glad to delegate less clinically exciting tasks.¹²⁶ However, physicians in New Zealand also respected the specialist skills of nurses and dietitians, who really did have a different approach to diabetes than the traditional medical model. The NZSSD encouraged

¹²³ Sue Pollard, Interviewed by C.E. Harper, 24 November 2011.

¹²⁴ Pat Carlton, Interviewed by C.E. Harper, 31 August 2011.

¹²⁵ Price, 'The role of the dietitian in a multi-disciplinary team', p.23.

¹²⁶ Moore, pp.160–6.

their higher training and professional status and included them as near-equals, even though this generated professional rivalries.

Community-based services also generated professional rivalries: general practitioners were initially suspicious about hospital staff entering the community, which they saw as their territory. Professional education thus became as important as patient education; after all, many doctors expressed a greater desire to learn more about diabetes in the 1970s. The education centres in Christchurch and Auckland encouraged general practitioners and practice nurses to take more responsibility in diabetes management. Primary care representatives sat on the centres' management committees and attendance at the professional education courses increased, which suggests support for the principles of 'self-sufficiency'.

Consumer groups also shared a vision of self-sufficiency. Indeed, it is doubtful whether the education centres would have emerged when they did without the support of the Christchurch and Auckland diabetes societies, considering administrative resistance and funding difficulties. While the new educational philosophy may have constituted what medical geographer Laurie Brown called 'an extension of medical interests into daily life', lay diabetes societies took an active part in shaping the perspectives of health professionals as well as people with diabetes.¹²⁷ As Mary Robinson, the first co-ordinator of the Auckland Diabetes Centre noted, 'the staff have learnt a great deal and been heartened by the help provided by the patients themselves'; these staff did not view their patients as bio-signs.¹²⁸

When Laurie Brown suggested diabetes education was a form of social control in her 1988 doctoral thesis, she was not so much concerned with its philosophical basis, but the

¹²⁷ Brown, 'Organizational Influences on Diabetes Related Hospitalization', p.192.

¹²⁸ Auckland Diabetes Education Advisory Service First Annual Report, September 1982 to December 1983, p.5.

assumptions of improved health outcomes and reduced hospital utilisation on which education programmes gained widespread appeal. Looking at the international literature, there appeared to be little evidence to suggest long-term benefits from education alone; where reduced hospitalisations had occurred, there had usually been an accompanying reorganisation of services.¹²⁹ Brown was a research fellow in Beaven's academic medical unit at Princess Margaret Hospital and, with Dr Russell Scott, had conducted operational and epidemiological research on insulin-treated diabetes in Canterbury. Even though Canterbury had the most comprehensive diabetes services in the country, this research found persistent problems with the division of primary and secondary care, patterns of referral and under-resourcing, which undermined the potential benefit of education beyond the select groups who gained access to specialist – both treatment and educational – services. Beaven, Scott and Brown argued that, 'The new challenge is to reorganise diabetes care and to integrate diabetes education within the health service so that the full benefits of structured health delivery can be felt by all diabetic individuals.'¹³⁰ An ad hoc approach to diabetes in New Zealand would no longer be sufficient; the next two chapters investigate how this idea gained policy traction at a national level in the 1980s and 1990s.

¹²⁹ Brown, 'Organizational Influences on Diabetes Related Hospitalization', pp.198–205, 223, 461–82.

¹³⁰ Donald W. Beaven, Russell S. Scott and Laurie J. Brown, 'Diabetes care – a continuing challenge', *Australian and New Zealand Journal of Medicine*, 18, 3, 1988, p.18.

CHAPTER FIVE

‘A Health Problem for the 1980s’: politicising diabetes

*New Zealand has a very real problem: it must be accepted that money needs to be spent if the increasing health costs of diabetes mellitus is [sic] to be minimised. But time is against us ... we cannot afford to delay any longer.*¹

In 1983, a new diabetes organisation, the New Zealand Diabetes Foundation (NZDF), produced an extensive plan outlining why diabetes was ‘a health problem for the 1980s’ and what needed to be done about it. The NZDF, like the Diabetic Association of New Zealand (DANZ) and the organisation of diabetes health professionals, the New Zealand Society for the Study of Diabetes (NZSSD), perceived a lack of public awareness about diabetes, inadequate availability of up-to-date treatment and education services, and insufficient funding for research for which a ‘piecemeal ad hoc approach’ would no longer suffice.² Professor Donald Beaven predicted that without a significant investment of human and financial resources in these areas, ‘An epidemic of diabetes, preventable in its devastations ... [was] ahead of us all.’³ For many years New Zealand’s leading medical expert on diabetes, Beaven now saw himself as an ‘ageing activist’ and would initiate advocacy efforts to politicise diabetes in the 1980s.⁴

This chapter discusses how, and to what effect, diabetes organisations publicised a diabetes problem in New Zealand in the 1980s, a decade of economic crisis and political change. It examines the formation of the NZDF, restructuring of the DANZ, and the NZSSD’s contribution to two significant government initiatives for diabetes: the development of

¹ NZDF, ‘Diabetes in New Zealand: A Health Problem for the 1980s’, p.3, Diseases – Diabetes, 1981–84 ABQU 632 W4415 267/ 131/20, (56669), Archives New Zealand, Wellington (ANZW).

² P.J. Dunn to Dr M.E.R. Bassett, 3 April 1985, Diseases – Diabetes, 1984–86, ABQU 632 W4452 667/ 131-20 (60257), ANZW.

³ D.W. Beaven, ‘NZSSD President’s Report 1984–85’, 13 May 1985, D.W. Beaven Papers, Accession #195, 36788, Macmillan Brown Library, Christchurch (MBL).

⁴ Flora Davidson to Beaven, 17 January 1979, D.W. Beaven Papers Accession #195, 36755, MBL.

diabetes service planning guidelines for Area Health Boards (AHBs) and the establishment of a Medical Research Council (MRC) Diabetes Task Force. Sociologist Steven Epstein has argued that the impact of health advocacy may not just be in direct policy outcomes and scholars should consider its wider cultural effects, unanticipated changes and long-term consequences.⁵ Thus, this chapter looks broadly at the impact diabetes advocacy had on the political and public profile of diabetes in New Zealand.

A new organisation to address ‘this major health problem’: the NZDF

By the end of the 1970s, diabetes advocates had concerns about the level of funding for diabetes education and research in New Zealand. The National government (1975–84) restricted growth to Vote Health in its second term because of deteriorating economic conditions and the rising costs of healthcare. Moreover, the funding and structure of the hospital board system was under review and politically contentious.⁶ The MRC funded few diabetes projects and DANZ’s National Research Fund could only support one research fellow and small supplementary research or conference travel grants. Meanwhile, the United States had increased investment in diabetes research and training, and the World Health Organization (WHO) called for other countries to do the same as diabetes prevalence increased around the world. The DANZ and its medical advisors believed there was a need for large-scale, co-ordinated fundraising to address ‘this major health problem’ in New Zealand, and a diabetes foundation was the answer.⁷

⁵ Steven Epstein, ‘Measuring Success, Scientific, Institutional and Cultural Effects of Patient Advocacy’, in Beatrix Hoffman, Nancy Tomes, Rachel Grob and Mark Schlesinger, eds, *Patients as Policy Actors*, New Brunswick, 2011, pp.257–70.

⁶ Derek Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Health*, Wellington, 1995, pp.214–20.

⁷ NZDF, ‘Diabetes in New Zealand: A Health Problem for the 1980s’, p.2.

The initial impetus for the NZDF was a new phenomenon in fundraising – the telethon. Referencing the newly popular endurance sport of marathon running, telethons began in New Zealand in the 1970s. They drew on the power of television to turn fundraising and awareness campaigning into a competitive sport: professional entertainers and ordinary people vied for donations for the nominated cause by performing carnivalesque stunts, physical challenges and impersonations.⁸ The DANZ began looking into being a beneficiary organisation after the success of the first telethon in New Zealand in 1975 for John's Ambulance. It appointed a sub-committee of the Christchurch Diabetes Society to investigate the telethon application process. The sub-committee reported back to the DANZ that competition was rigorous and the DANZ would need to project itself as a nationally relevant organisation to be successful.⁹ Beaven and Garth Harris, Secretary of the Christchurch Society and the DANZ's Vice President, argued a standalone trust would be most attractive to telethon organisers. Early in 1979, they formed a steering committee and worked with a solicitor on a constitution for a diabetes foundation.¹⁰ The DANZ's Medical Advisory Panel attracted notable business people to serve as founding board members.¹¹ Sir Charles Burns, the first doctor to administer insulin in a New Zealand hospital, became Trustee and former Prime Minister Sir John (Jack) Marshall, served as Patron.¹² The Medical Panel decided on a decentralised structure with sub-committees in the main regional centres focusing on different aspects of the diabetes

⁸ Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, Wellington, 2007, p.160.

⁹ Minutes of a Meeting of the Executive of the DANZ, 4 September 1978, pp.2–3, Diabetes New Zealand, Wellington (DNZ).

¹⁰ Minutes of the Annual General Meeting of the DANZ, 10 March 1979, p.6, DNZ.

¹¹ The NZDF's founding board members were Cyril Keppel (Deputy Chairman of Air New Zealand), Donald McLeod (Chairman of Watties), H.W. Revell (Farmers Trading Company) and Graham Valentine (AMP board member).

¹² Sir Charles Burns to Sir John Marshall, 8 May 1979, Subject file - New Zealand Diabetes Foundation Inc. 1979-1984, Sir John Marshall, 1912-1988: Further papers (98-116), 98-116-03/14, Alexander Turnbull Library, Wellington (ATL).

advocacy, such as research, social welfare and publicity.¹³ The Christchurch sub-committee would work on an application for the 1981 telethon.¹⁴

The NZDF sought to model itself on the National Heart Foundation (NHF), an organisation that had achieved significant public and political influence.¹⁵ A group of New Zealand cardiologists and surgeons formally established the NHF in 1968.¹⁶ The medical founders attracted lay members through a regional committee structure responsible for fundraising. In 1969, the NHF's first fundraising appeal amassed a substantial sum of \$860,000. That year the NHF established a Scientific Committee to evaluate research projects for funding, and the following year a Publicity Committee. Over the 1970s the NHF grew rapidly, instituting research fellowships, health education initiatives, funding the first national dietary survey, and publishing technical reports for professionals.¹⁷ The NZDF believed that the NHF's success was because of its single-issue advocacy at a national level and promoted this approach for the NZDF.¹⁸

The NZDF also positioned its plan to 'launch a co-ordinated attack' on 'the medical, social and economic aspects' of diabetes with the increased international attention on the disorder.¹⁹ Beaven had attended the tenth International Diabetes Federation (IDF) congress in Vienna in 1979 and an associated WHO epidemiology meeting. Following this, in a promotional brochure entitled, 'Why a foundation for diabetes?' Beaven highlighted that the WHO had

¹³ Minutes of a Meeting of the Medical Advisory Panel of the DANZ, 7 March 1980, p.2, Personal Collection of Dr Bob Smith.

¹⁴ Garth Harris, Secretary of the Executive Committee of the NZDF to All Board Members and Sub-Committees, 3 June 1980, (98-116), 98-116-03/14, ATL.

¹⁵ Perhaps not coincidentally, Sir John Marshall was also Patron of the NHF.

¹⁶ There had been interest in establishing the organisation since the launch of Australian Heart Foundation in 1958: Sir David Hay, *Heart Sounds: A Life at the Forefront of Health Care*, Wellington, 2005, p.109.

¹⁷ NHF, *21 Years: The National Heart Foundation of New Zealand 1968–1989*, Auckland, 1989, pp.5–6.

¹⁸ Malcolm Watson, 'The New Zealand Diabetes Foundation Inc.', *N.Z. Diabetic Review*, 16, 2, July 1979, p.20.

¹⁹ Report for telethon application, p.5 encl. with Harris to All Board Members and Sub-Committees, 3 June 1980, (98-116), 98-116-03/14, ATL.

declared diabetes one of its top five international diseases and a major problem for the Pacific Basin. Additionally, it noted how the United States Federal government had declared diabetes its third major health problem behind heart disease and cancer.²⁰

In the United States, the Nixon administration had introduced legislation in 1974 that mandated the development of a Long Range Plan to Combat Diabetes. Released in 1975, the plan attempted a comprehensive approach to the disorder's treatment, social and public health impact, with a particular focus on the secondary prevention of diabetes complications. It introduced federal funding for Diabetes Research and Training Centres, which combined clinical, laboratory and professional training services in a single institution and practiced the new concept of translational research: the Centres would undertake all the steps to translate research results into clinical practice.²¹ Beaven looked to the United States as a model for patient education and research; the Christchurch Diabetes Centre with its relationship to researchers in his academic medical unit was the closest New Zealand had to the United States model. However, as the last chapter indicated, this was not an integrated or comprehensively planned approach. The NZDF's telethon application proposed the development of 'centres of excellence for diabetes research and training' at the existing university-affiliated hospital departments in Auckland, Wellington, Christchurch and Dunedin as part of 'a long range plan to combat diabetes'.²²

²⁰ NZDF, 'Why a Foundation for Diabetes?', (98-116), 98-116-03/14, ATL. Beaven had written the text before the IDF meeting and Wellington physician Dr Malcolm Watson adjusted the details after hearing Beaven discuss it on the radio.

²¹ On these developments, including the re-tooling of American diabetes advocacy in the 1970s, see Aaron Mauck, 'Managing Care: The History of Diabetes Management in Twentieth Century America', PhD dissertation, Harvard University, 2010, pp.304–33; James Wright Presley, 'A History of Diabetes Mellitus in the United States, 1880-1990', PhD dissertation, University of Texas, 1991, pp.391–406; Stephanie Stegman, 'Taking Control: Fifty Years of Diabetes in the American Southwest 1940-1990', PhD dissertation, Arizona State University, 2010, pp.120–63.

²² Report for telethon application, pp.5–6.

The inaugural meeting of the NZDF in Wellington in August 1980 was an opportunity to publicise both the local and international importance of addressing the diabetes problem. The Medical Panel's Dr Malcolm Watson, a diabetes physician and AMP's Chief Medical Officer, had arranged the meeting, held in the AMP boardroom, to coincide with a postgraduate course on diabetes where there would be several eminent overseas speakers.²³ The Minister of Health, George Gair, opened the meeting with a speech that acknowledged diabetes was an increasing health problem in New Zealand, but claimed he could not offer additional resources to diabetes while he maintained real health expenditure at current levels. Instead, he praised the Foundation as a way to supplement government services.²⁴ The international guests addressed the meeting with encouragement for 'those present to aim high so that New Zealand could be in the forefront of research and patient care'.²⁵ The meeting went on to elect AMP board member Graham Valentine as Chairman, a Wellington-based Executive Committee and decided to make a determined effort to bring to the 'general populace's attention, problems connected with diabetes'.²⁶

The way the NZDF presented these problems to the public demonstrated the difficulties of single-issue advocacy for an increasingly complex disorder. On the Sunday evening following the Foundation's inaugural meeting, the current affairs programme *Close Up* screened a feature story 'Diabetes – Sugar Sickness'. The programme clearly meant to establish diabetes as a serious public health problem: it opened with the claim diabetes was New Zealand's third biggest killer and that the incidence of the disorder was expected to increase with rising rates

²³ D.W. Beaven, 'Memorandum on New Zealand Diabetes Foundation', 5 December 1979, Personal Collection of Dr Bob Smith.

²⁴ 'Final Speech Notes to Address the Inaugural Meeting of the New Zealand Diabetes Foundation', ABQU 632 W4415 267/ 131/20 (52881), ANZW.

²⁵ Malcolm H. Watson, 'The New Zealand Diabetes Foundation Inc. inaugural meeting held on August 14 1980: promising new era in education and research', *N.Z. Diabetic Review*, 17, 3, October 1980, p.4.

²⁶ Minutes of the Inaugural Meeting of the NZDF, 14 August 1980, Personal Collection of Dr Bob Smith.

of obesity.²⁷ Yet, there was also a tension with the traditional anti-discrimination focus of advocacy – that people with diabetes could live normal lives – and a new stress on the need to improve treatments and means to prevent complications. It presented the trials and tribulations of living with insulin-dependent diabetes (IDDM) with the stories of how four-year old Craig’s parents dealt with his care and how teenage Susan battled to accept her diagnosis. The film highlighted the promising advances of artificial insulin delivery and glucose monitoring, and even the potential curative transplantation of pancreatic islet cells if more research could be funded. It promoted the new educational approach of the Christchurch Diabetes Centre. Beaven explained the seriousness of diabetes complications and called for education equivalent to that for heart disease: ‘we already have to tell all New Zealanders they will get hardening of the arteries because our diets are terrible. Our job today is to convince doctors, politicians and community people to keep blood sugars normal.’²⁸ The example of Barry Wilson personified the consequences of inaction: diagnosed at age forty, ten years later he was completely blind, had suffered from gangrene, endured multiple skin grafts, lost three toes and expected an early death.

The NZDF did not sustain a media presence and encountered limited success with its early fundraising, particularly in comparison with other serious diseases. The NZDF’s telethon application was unsuccessful, as the telethon organisers decided to go with a ‘disability’ theme to mark International Year of the Disabled. Were people with diabetes ‘normal’ or ‘disabled’? The NZDF felt that it lacked the data to make a case for the latter.²⁹ In the absence of telethon fundraising, the NZDF relied on individual and corporate memberships and donations, mainly from a letter-writing appeal to contacts of the founding executives on its

²⁷ This often-repeated claim in the 1980s referred to the inaccuracy of diabetes mortality statistics, which hid diabetes contribution to deaths from other causes, particularly heart disease and stroke.

²⁸ *Close Up: Diabetes – Sugar Sickness*, 17 August 1980, Television New Zealand Archives, Wellington (TVNZ).

²⁹ Sir John Marshall to Garth Melville, 13 October 1980 (98-116), 98-116-03/14, ATL.

Board.³⁰ At the end of the 1982 financial year, the NZDF had raised only \$27,000, which it attributed to competition from a major Cancer Society media campaign that overshadowed its letter-writing efforts: the Cancer Society's 1981 'Cancer Alert' campaign raised \$2.5 million.³¹ Cancer had a well-established public image as a common and feared disease, which attracted such charitable, and government, investment in research funding.³² The NZDF's Christchurch sub-committee attempted another telethon application for 1983, however, when this also failed its chairperson H.W. Revell suggested the Foundation should seek advice on 'specific image improvement': 'I have wondered whether diabetes has a difficult image ... to develop a theme which would motivate sympathy'.³³

In 1983, Beaven took six months overseas sabbatical where he gathered new evidence and inspiration he would use to invigorate the NZDF's appeals. Beaven was an internationally recognised expert in diabetes care and took the position of Visiting Professor at Guys Hospital, London, the University of Padua in Italy, and the Institute for Diabetes for Developing Countries Zagreb Academy of Medicine in Yugoslavia.³⁴ He also spent time in the United States at the Bethesda National Institute of Health Diabetes Division in Maryland. While there he saw some of the Federal government funding for diabetes in action, and compiled extensive data on diabetes services and epidemiology.³⁵ On returning from his sabbatical Beaven thanked the doctors at Bethesda and informed them that he was busy preparing a plan with the Christchurch Sub-committee for the NZDF to present 'to

³⁰ Watson, 'The New Zealand Diabetes Foundation Inc. inaugural meeting held on August 14 1980', pp.4–5.

³¹ Minutes of a Meeting of the Executive Committee of the NZDF, 3 May 1982, pp.1–2; 'History of the Society', n.d., URL: <http://www.cancernz.org.nz/about-us/history/>, accessed 13 October 2011.

³² Patrice Pinell, 'Cancer', in Roger Cooter and John Pickstone, eds, *Companion to Medicine in the Twentieth Century*, London, 2003, pp.671–85.

³³ 'Report to the Annual General Meeting of the NZDF from the Chairman of the Christchurch Sub-committee', 1983, (98-116), 98-116-03/14, ATL.

³⁴ K.G.M.M. Alberti asked Beaven to do the chapter on organisation of diabetes care for the important international publication Alberti edited, *Diabetes Annual*, because of his recognised expertise: Alberti to Beaven, 11 October 1983, D.W. Beaven Papers, Accession #195, 36655, MBL; Professor D.W. Beaven Curriculum Vitae, c.1984, D.W. Beaven Papers, Accession #195, 36823, MBL.

³⁵ D.W. Beaven Papers, Accession #195, 36842, MBL.

government, and to which considerable controversy will arise'.³⁶ By this point in his career, Beaven was an outspoken critic of health bureaucracy and wrote what he called 'provocative articles' for both popular and professional audiences on health policy.³⁷ Publicly stating in the *Christchurch Star* in June 1983 that New Zealand was falling behind other countries in its diabetes services, Beaven was setting up to pressure the government to act.³⁸

This pressure would come in the form of 'Diabetes in New Zealand: A Health Problem for the 1980s'. The plan claimed the United States were on track to conquer diabetes in the next decade with its government investing almost \$200 million per year in research and education. By contrast, the plan criticised the New Zealand government's apparent apathy: the WHO now considered diabetes 'the single most important health problem in the Pacific', yet 'health advisors and government here in New Zealand have been unusually slow to move'.³⁹

Moreover, 'New Zealand senior health administrators' were unaware of the health impact of diabetes, that it was treatable and that there was potential for greatly reducing its social and economic impact.⁴⁰ The plan estimated a minimum of 100,000 New Zealanders had diabetes and that diabetes cost \$120 million a year in hospital costs alone. It reiterated the desirability of regional United States-style research and training centres, and education centres such as in Christchurch. Self-care was 'to be vigorously pursued', as well as early diagnosis and intervention. The plan provided a detailed breakdown of staffing requirements and costs of

³⁶ Beaven to Dr L. Lipsett and Dr K. Kruger, 15 July 1983, D.W. Beaven Papers, Accession #195, 36652, MBL.

³⁷ D.W. Beaven, 'Failure of school health education: cultural neglect or political rigidity', NZMJ, 94, 693, 14 October 1981, p.268. For example newspaper clippings, see D.W. Beaven Papers Accession #195, 36821, MBL. The quote is from, Beaven to Michael Forbes, 17 January 1980, D.W. Beaven Papers Accession #195, 36660, MBL.

³⁸ 'Health second to racing, beer – Professor', *Christchurch Star*, 29 June 1983.

³⁹ NZDF, 'Diabetes in New Zealand: A Health Problem for the 1980s', p.2. Beaven had been New Zealand representative at a WHO Western Pacific Region meeting in Fiji in 1982 to plan interventions and direct resources to address the rapid increases in diabetes in Pacific countries. The plan envisioned the secondment of Pacific health professionals to New Zealand diabetes research and training centres to enable them to take advanced diabetes management skills back to their home countries.

⁴⁰ *Ibid.*

\$1.9 million per year. Predicted future savings of more than \$10 million per annum in inpatient hospital expenditure, however, would offset these costs.⁴¹

Despite the plan's apparent economic logic government officials declined to fund it. A NZDF deputation presented the plan to the Director-General of Health, Dr Ronald Barker, in November 1983 and requested that it be included in the Health Department's 1984 budget submissions. Barker informed the deputation he was unable to commit funds because of the government's spending restrictions.⁴² On learning this, Beaven told diabetes health professionals, 'I was most disappointed an extremely well organised and worked out proposal for expanding government spending on diabetes was received rather coolly [sic] by the Director General of Health' who 'was extremely lukewarm in his reception' of the deputation.⁴³ He argued the proposal was 'extremely imaginative' but also 'realistic' considering the government's current spending on drugs and hospitalisation of people with diabetes. Barker subsequently wrote to Beaven that he regarded the criticisms about his Department's ignorance of diabetes treatment 'as a serious reflection on me and my staff and I stated this quite clearly to the people who visited me ... a good cause such as they were proposing was not to be supported by denigrating one's colleagues'.⁴⁴ Indeed, the NZDF's approach appeared a departure from the usually co-operative working relationship with the Department through the DANZ Medical Panel and its co-opted Departmental representative.⁴⁵ After their meeting with Barker, the Foundation met with the Minister of Health, Aussie Malcolm, who simply reiterated that 'there were great demands on limited funds'.⁴⁶

⁴¹ These savings were based on projections from studies of IDDM inpatient reductions following the establishment of the Christchurch Diabetes Centre: NZDF, 'Diabetes in New Zealand: A Health Problem for the 1980s', pp.14–15.

⁴² Barker to Beaven, 29 May 1984, D.W. Beaven Papers, Accession #195, 36856, MBL.

⁴³ D.W. Beaven, 'Presidential Address', *NZSSD Newsletter*, 22, 26 March 1984, pp.1–2.

⁴⁴ Barker to Beaven, 29 May 1984.

⁴⁵ See Chapter Two.

⁴⁶ Minutes of the Annual General Meeting of the DANZ, 17 March 1984, p.3, DNZ, Wellington.

Following this, the NZDF did not pursue government funding and Beaven became less active in the organisation.⁴⁷

Even though the NZDF's national campaigning was short-lived, in 1986 it established a new diabetes research fellowship, which had a long-term influence on diabetes as a public health policy issue. Dr Malcolm Watson secured from the AMP Society (through his position as Medical Officer for the company) substantial funding for a research fellowship. The NZDF allocated and administered the AMP fellowship to physicians undertaking postgraduate training in diabetes. Between 1987 and 1996, the Foundation awarded nine recipients awards of between \$30,000 to \$45,000 per year.⁴⁸ Watson later reflected that 'it certainly deserved more publicity than it got – this [i.e. the fellowships] made a big impact'.⁴⁹ A number of the recipients became important figures in diabetes medicine in the 1990s and 2000s. The first, Dr Robyn Toomath, established a successful career as an endocrinologist, before she entered the new millennium as the public face of anti-obesity campaigning.⁵⁰

While the NZDF played an important part in developing diabetes expertise in New Zealand, the more zealous advocate, Beaven, believed diabetes needed a sustained, high profile political attack to attract more government funding. As the NZDF's early fundraising experience demonstrated, organisations for more feared and prominent diseases proved tough competition: diabetes organisations needed to convince the public and politicians diabetes was an equally serious problem.

⁴⁷ Beaven recalled several years later that his hard work in attracting key Christchurch business people suffered under leadership from Wellington where he claimed 'inertia prevailed': Beaven to Murray Jones and Lee McLeod, n.d. (c.1990), D.W. Beaven Papers, Accession #195, 36826, MBL. Beaven went on to establish the Christchurch-based Diabetes Training and Research Trust in 1991.

⁴⁸ Dawson, p.113.

⁴⁹ Ibid.

⁵⁰ Dr Robyn Toomath, Interviewed by C.E. Harper, 11 March 2013. See also Chapter Six.

‘Strength through Unity’? The DANZ’s restructuring and publicity in the mid-1980s

In the mid-1980s, the leadership of the diabetes organisational movement perceived fragmented interest groups as a major obstacle to greater political and public recognition of diabetes, and their ability to compete within a crowded advocacy space. This was not unique to New Zealand. F.I.R. Martin noted in his history of diabetes in Australia that the Diabetes Federation of Australia, which was established in 1956, was a ‘national body in name alone’; by the early 1980s Australia had new foundations supporting diabetes research, and separate lay, youth, medical and educator bodies. The Australian organisations agreed to unify in 1983 to overcome difficulties in lobbying government and fundraising.⁵¹ The new DANZ President Garth Harris wondered if New Zealand’s organisations, like their Australian counterparts, could achieve what the title of a restructuring proposal called, ‘Strength through Unity’.⁵²

By 1984, the DANZ was supposedly an umbrella organisation co-ordinating 24 local diabetic societies. The DANZ encouraged the growth of these local societies, but provided them with no real operational or strategic guidance. Consequently, the local societies had substantial autonomy.⁵³ There was also the professional body the NZSSD, which had considerable functional overlaps with the DANZ’s Medical Advisory Panel. In 1984, the Panel changed its name to the Professional Advisory Panel to encourage non-physician health professional input; the Panel planned to eventually disband and for the NZSSD to take on its advisory role to the DANZ.⁵⁴ The newest organisation, the NZDF, was a separate fundraising body but had cross-representation from the other groups.

⁵¹ The unification was not complete, however, until 1987: F.I.R. Martin, *A History of Diabetes in Australia*, Melbourne, 1998, pp.52, 75–79.

⁵² ‘Strength through Unity: Report of the Committee Investigating Possible Restructuring of the Association’, 1985, DNZ.

⁵³ Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011; Dawson, p.45.

⁵⁴ ‘News from the Annual General Meeting of the DANZ and the Medical Advisory Panel, 16–17 March 1984’, *NZSSD Newsletter*, 22, 26 March 1984.

Meanwhile, the Auckland Diabetic Society was completely autonomous, as it had left the DANZ in December 1981. Ambitious and well managed, the Auckland Society believed its members received nothing for their levy to the national body and wanted more influence nationally.⁵⁵ In 1983 the Society had opened its community education centre with the Auckland Hospital Board and, to the DANZ leadership, appeared to have made great strides in local education and detection efforts; the DANZ Executive knew it needed the Auckland Society to have an impact ‘on the national scene’ and began negotiations for it to re-affiliate.⁵⁶ The DANZ’s 1984 annual general meeting established a restructuring sub-committee to investigate ways to address the Auckland Society’s concerns and generally enhance unity, local representation and minimise duplication of services between local societies and the national organisation.⁵⁷

The 1984 annual general meeting also elected Harris as president, who was eager to build up diabetes’ national profile. Harris had been a key figure in establishing the diabetes movement in New Zealand; in 1979, he was recognised with an MBE for services to people with diabetes.⁵⁸ He also had well-established links with the health services in Christchurch through his position on the Management Committee of the Christchurch Diabetes Centre. Russell Finnerty, who would succeed Harris as president in 1987, described Harris as having done a ‘superb’ job bringing together his Christchurch connections, business background and ‘terrific vision’ for the Association, especially considering his deteriorating health.⁵⁹ Harris saw a strong national organisation as key to effective diabetes advocacy and argued that the DANZ should learn from ‘the rapid growth and impact of some of the newer similar organisations [to

⁵⁵ Minutes of Meeting of the Executive of the DANZ, 10 December 1983, p.1, DNZ.

⁵⁶ Annual Report of the DANZ for the year ended 31 December 1983, p.2, DNZ.

⁵⁷ Minutes of Annual General Meeting of the DANZ, 17 March 1983, pp.6–10, DNZ.

⁵⁸ Annual Report of the DANZ for the year ended 31 December 1979, p.3, DNZ.

⁵⁹ Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011. Harris died in 1988.

the DANZ] in New Zealand (such as the Asthma and Arthritis Foundations)'.⁶⁰ He also commented approvingly on the recent unification of diabetes organisations in Australia that had 'effectively encouraged the Federal Government to fund a Diabetes Secretariat in Canberra!' Harris determined a top priority for the DANZ was to establish a national office with a full-time secretary.⁶¹

By the time of the DANZ's next annual general meeting in March 1985, the organisation had formulated its restructuring plan, 'Strength through Unity'. The plan recommended the formation of regional and specialist committees with representation on the National Executive, 'more intense' national publicity, fundraising and co-ordination of resources and the establishment of a national secretariat.⁶² The organisation would change its name from the Diabetic Association to the New Zealand Diabetes Association (NZDA). This reflected that the organisation was not just for people with diabetes: it was for all groups with an interest in the disorder and its public health impact.⁶³ Thus, the NZSSD, NZDF and Professional Advisory Panel would be affiliated into the NZDA. The meeting approved the plan and the Auckland Society agreed to re-affiliate.⁶⁴

The significance of the plan extended beyond the organisation. The new Labour government's Deputy Prime Minister Geoffrey Palmer addressed the meeting, which the nightly television news reported on.⁶⁵ Palmer told the NZDA that with a strong national body, the NZDA would get greater media attention, better understand the decision-making process of government and

⁶⁰ Annual Report of the DANZ for the year ended 31 December 1984, p.2, DNZ.

⁶¹ Ibid.

⁶² 'Strength through Unity', p.1.

⁶³ Ibid., p.3.

⁶⁴ Minutes of Annual General Meeting of the DANZ, 9 March 1985, pp.7–10, DNZ.

⁶⁵ 6:30pm News, 9 March 1985, TVNZ.

could become a policy player.⁶⁶ He implied government spending would be dependent on such changes. Harris warned that the NZDA ‘could not expect a golden handshake’ from government, or anyone else, and that the national body would only survive ‘with the active support of every member society’.⁶⁷

Harris’ statement was indicative of the financial and structural difficulties the NZDA faced. In August 1985, the NZDA appointed John Rutherford as its first full-time salaried manager and soon after leased him a Wellington office, on the condition that local societies would not have to contribute to the costs of running the office. Rutherford reported to the NZDA Executive that he found local societies’ reservations to ‘nationalisation’ meant he struggled to co-ordinate their activities and undertake the major media and fundraising activities he planned.⁶⁸ In any case, his appointment ended abruptly after one year due to allegations of financial impropriety.⁶⁹ Harris argued in the NZDA journal that this was only ‘an initial setback’ and the organisation would re-establish a national office when resources improved.⁷⁰ In the meantime, Murray Jones of the Oamaru Diabetic Society took on secretarial duties part-time from his own home-based secretarial business. From an organisational perspective, the NZDA achieved neither strength nor unity in the 1980s.

Despite the challenge of disunity, the NZDA did expand its publicity and public relations with a new approach to awareness campaigns. The DANZ had run national diabetes awareness weeks since 1976, but these typically suffered from under-resourcing and a lack of local

⁶⁶ Minutes of Annual General Meeting of the DANZ, 9 March 1985, pp.1–2, DNZ.

⁶⁷ Annual Report of the DANZ for the year ended 31 December 1985, p.2, DNZ.

⁶⁸ *Ibid.*, pp.5–6.

⁶⁹ Murray Jones, Interviewed by C.E. Harper, 9 November 2012; Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

⁷⁰ Garth Harris, ‘National news’, *Diabetes Review*, 23, 3, December 1986, p.1.

society co-ordination and participation.⁷¹ In March 1986 Russell Finnerty, a long-serving National Executive member who had just returned from three years working in Fiji, took up the Publicity and Public Relations portfolio.⁷² Finnerty, who had a professional background in project management, began groundwork for the major public relations campaign, Diabetes Awareness Month in November 1986. Prior to leaving the organisation, Rutherford had organised Miles Laboratories (Ames) to sponsor a media brief and media information kits, as well as donate blood glucose meters for each local society to raffle off.⁷³ The Labour Member of Parliament (MP) for Napier Geoff Braybrooke (who had diabetes) launched the campaign at this media brief. After previous failed national awareness weeks, the NZDA recognised that ‘T.V. support was needed if we were to make Awareness Month successful’ and subsequently contributed to stories on diabetes on the *6.30pm News* and *Today Tonight*.⁷⁴

The 1986 Awareness Month differed markedly in its representation of diabetes from previous awareness campaigns. While the traditional theme of awareness campaigns was living ‘a full life despite diabetes’, in 1986, television features, magazine articles and journal editorials presented an additional motif: that diabetes was an underestimated, expensive, yet preventable national health problem.⁷⁵ The campaign presented data about the increased prevalence of diabetes with the population ageing, fattening, and including more Maori and Pacific peoples. It attempted to shift the common belief that non-insulin-dependent diabetes (NIDDM) was

⁷¹ Although the regular annual diabetes weeks began in 1976, the first national campaign was in conjunction with the Health Department to commemorate the fiftieth anniversary of the discovery of insulin in 1971: see Chapter Two. Some societies held local detection and awareness weeks earlier, such as Auckland, which began in the mid-1960s: see Chapter Three.

⁷² Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

⁷³ NZDA Management Plan for 1986, 17 July 1986, p.11, DNZ.

⁷⁴ Minutes of the Annual General Meeting of the NZDA 15 March 1986, p.8, DNZ; *6:30pm News*, 29 October 1986; *Today Tonight*, 30 October 1986, TVNZ.

⁷⁵ D.W. Beaven, R.S. Scott, M.P. Moore and F.J.M. Iris, ‘Diabetes awareness’, *NZMJ*, 99, 812, 22 October 1986, p.802; R.S. Scott, M.P. Moore, D.W. Beaven and L.J. Brown, ‘Editorial: Diabetes in New Zealand 1986’, *Journal of the N.Z. Dietetic Association*, 40, 2, October 1986, p.58; Lynne Loates, ‘Diabetes: the ultimate balancing act’, *More*, November 1986, pp.171–9; *6:30pm News*, 29 October 1986; *Today Tonight*, 30 October 1986, TVNZ.

‘mild’, by highlighting its long-term complications and high hospitalisation rates. The extent of the change of image was evident in the feedback to Finnerty on the posters disseminated to local societies. He reported that, ‘Some societies considered these posters to be too negative’ but ‘the intention was to bring to the notice of the public of New Zealand the high social and medical cost of the preventable complications of diabetes’.⁷⁶

Diabetes advocates had at least nominal political recognition of their cause. The Christchurch Diabetes Society published a template letter in its newsletter for members to post to their MPs during awareness month; the letter stressed the hidden costs of diabetes to the health services through its complications and requested politicians to show greater awareness.⁷⁷ Health Department officials appeared to accept the figures, yet they still warned the Minister of Health, Michael Bassett, that he ‘should give nothing away – consideration, but not promises’ when Bassett spoke at an NZDF event during the awareness campaign.⁷⁸ While not as tangible an outcome as funding, Braybrooke’s involvement was still important for public health messages about diabetes: he discussed the growing incidence of diabetes and that people ‘at risk’ should get their blood sugar levels tested regularly.⁷⁹ The *New Zealand Herald* reported that Braybrooke ‘was sure some of his colleagues would have diabetic tendencies’ as they ‘showed signs of diabetes such as irritability, rashness and exhaustion’.⁸⁰ Braybrooke purchased an Ames blood glucose monitoring machine at the media briefing and said he would offer all MPs the chance to use it. Additionally, the Speaker of the House had

⁷⁶ Minutes of Annual General Meeting of the NZDA, 4 April 1987, p.8, DNZ.

⁷⁷ *Diabetes Viewpoint*, September/October 1986, pp.10–12.

⁷⁸ Bob Boyd, ‘Briefing Notes: AMP Diabetes Research Fellowship’, 25 November 1986, Primary Health Care – Diabetes, 1986–90, ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW.

⁷⁹ ‘Diabetes awareness: seminar to launch Diabetes Awareness Month’, *Diabetes Review*, 23, 3, December 1986, p.3.

⁸⁰ ‘Tests Offer for MPs on Diabetes’, *New Zealand Herald*, 27 October 1986.

provisionally approved a campaign to test MPs in parliament. Finnerty later arranged this campaign with a public relations firm for the next diabetes week in May 1987.⁸¹

Thus, although the NZDA faced ongoing issues with finance and organisational disunity, the 1986 diabetes awareness month marked an important shift in advocacy: the NZDA began to articulate a new image of diabetes – that it was a major, expensive health problem – which could engage political attention.

The NZSSD and diabetes service planning guidelines for Area Health Boards

Formed in 1976 to promote diabetes research, education and care amongst health professionals and scientists with an interest in diabetes, the NZSSD also came to have a political role in the mid-1980s. At a time when capping spending and increasing the efficiency of public services were key government concerns, the NZSSD sought to convince health authorities of the need to prioritise diabetes services.

Unsurprisingly, Beaven led the NZSSD to a more active, media-focused and political stance about the resources available for diabetes. The NZSSD had previously engaged in some lobbying of the Health Department over diabetes educator training, but Beaven wanted the NZSSD to adopt techniques of the American Diabetes Association, which he claimed stirred ‘widespread public interest in diabetes’ through ‘extremely good television coverage on a regular basis’.⁸² In New Zealand, Beaven instigated television news reportage of the NZSSD triennial conference held in Waikato in August 1983.⁸³ Beaven believed health professionals had a ‘public responsibility’ to court the media about diabetes, which he did in newspapers

⁸¹ Minutes of the Annual General Meeting of the NZDA, 4 April 1987, p.8, DNZ.

⁸² Beaven to P.J. Dunn, 5 July 1983, D.W. Beaven Papers, Accession #195, 36734, MBL.

⁸³ ‘Diabetes’, *6:30pm News*, 2 September 1983, TVNZ. On diabetes educator training, see Chapter Four.

and on radio.⁸⁴ In March 1984, in his role as NZSSD president Beaven claimed that five years of restrictions on government health spending had affected diabetes more greatly than ‘other more fashionable disorders such as heart disease, cancer and asthma’.⁸⁵ He requested that Society members ‘speak and act publicly to bring to the attention of all New Zealanders the fact that this [National government] and previous governments ... have not invested the sort of money in [diabetes] ... which is necessary if we are to prevent prolonged, wasteful and extravagant use of hospital resources’.⁸⁶ Beaven himself wrote to the Minister of Health, Aussie Malcolm, Minister of Customs, Keith Allen, and Minister of Police, Ben Couch. Couch and Allen, who both had diabetes, replied that they would try to raise awareness amongst ministerial colleagues.⁸⁷

Beaven capitalised on a scandal involving Allen to demonstrate that there was inadequate public spending on diabetes education. The scandal had erupted after Allen alleged he was attacked as he walked home late one night from parliament. On the night in question, a journalist had covertly filmed Allen, who appeared intoxicated. It turned out that Allen might have been hallucinating due to complications from mixing alcohol with his diabetes medication.⁸⁸ Allen died not long after the incident. In a television interview and newspaper article Beaven argued the ‘Allen affair’ showed the widespread ignorance that people with diabetes could ‘remain normal and perform well’ if properly educated and that there were insufficient education facilities to cope with the extent of diabetes in the community.⁸⁹

⁸⁴ D.W. Beaven, ‘NZSSD President Report’, 1984, D.W. Beaven Papers, Accession #195, 36819, MBL.

⁸⁵ D.W. Beaven, ‘NZSSD President Report’, 1984.

⁸⁶ D.W. Beaven, ‘Presidential Address’, p.2. Beaven served as NZSSD president from September 1983 to May 1985.

⁸⁷ Beaven to Malcolm, 18 May 1984, ABQU 632 W4452 667/ 131-20 (60257), ANZW; Allen to Beaven, 2 May 1984 and Couch to Beaven, 17 May 1984, D.W. Beaven Papers, Accession #195, 36856, MBL.

⁸⁸ ‘Drug put Mr Allen at risk’, *New Zealand Times*, 16 April 1984, D.W. Beaven Papers, Accession #195, 36856, MBL.

⁸⁹ Don Beaven, ‘Diabetes increasing’, press clipping in D.W. Beaven Papers, Accession #195, 36823, MBL.

In July 1984 a new Labour government entered office. With the country facing a three billion dollar deficit, high levels of inflation and expectations of increased public spending, the government responded to these challenges with radical restructuring of the economy.⁹⁰ The Finance Minister, Roger Douglas, and Treasury advisers prioritised economic growth through less government intervention into market forces.⁹¹ It was not immediately clear whether the government would introduce a market model into the health services; the new Minister of Health, Michael Bassett, battled with general practitioners over capping their fees and increasing the government subsidy for their services, but also commissioned a review of health benefits, to ‘report upon the underlying rationale for state involvement in health’.⁹²

A long-time Labour supporter, Beaven was ‘extremely hopeful’ that Bassett would ‘be sympathetic towards diabetes’.⁹³ Bassett had campaigned on increasing ‘community involvement in the planning and provision of health services’, which was also Beaven’s platform in his election to the North Canterbury Hospital Board in 1974.⁹⁴ At the prompting of the Professional Advisory Panel, in September 1984 the DANZ submitted to Bassett a request to set up a diabetes advisory committee. Bassett forwarded the proposal to the Board of Health for consideration when it met in January 1985.⁹⁵

Beaven’s optimism with the new government soon waned, however, as it became clear that Bassett considered that AIDS was a more pressing public health concern than diabetes. New

⁹⁰ Margaret McClure, *A Civilised Community: A History of Social Security in New Zealand, 1898–1998*, Auckland, 1998, p.211.

⁹¹ Christine Cheyne, Mike O’Brien and Michael Belgrave, *Social Policy in Aotearoa New Zealand: A Critical Introduction*, Auckland, 2000, pp.79–82.

⁹² Robin Gauld, *Revolving Doors: New Zealand’s Health Reforms – The Continuing Saga*, Auckland, 2009, pp.53–54.

⁹³ Beaven to L.P. Krall, 19 November 1984, D.W. Beaven Papers, Accession #195, 36651, MBL. Beaven had communicated about matters of health service organisation with Bassett while he was in opposition: Bassett to Beaven, 13 June 1984, D.W. Beaven Papers, Accession #195, 36856, MBL.

⁹⁴ New Zealand Labour Party, *1984 Policy Document: New Zealand Labour Party*, Wellington, 1984, pp.38–39.

⁹⁵ D.P. Short, Chairman of the Board of Health, to Bassett, 6 December 1984, ABQU 632 W4452 667/ 131-20 (60257), ANZW.

Zealand health authorities first learned about AIDS in mid-1981 through reports from the United States of homosexual men who had developed an unknown illness that affected the immune system and led to fatal infections. By late 1982, there were reports of cases outside the homosexual community that were contracted through transfusions and injecting drugs. New Zealand made AIDS a notifiable disease in September 1983.⁹⁶ During Bassett's first few months as Health Minister, he acted on the Health Department's advice and sent doctors to the United States and Australia to learn testing techniques, appointed an AIDS Task Force, and approved the testing of donated blood. In April 1985, Cabinet allocated nearly \$3 million to prevent the spread of AIDS, even though there were still no reported New Zealand-originating cases.⁹⁷ This allocation, on top of news the Board of Health would not set up a diabetes advisory committee, led Beaven to despair that diabetes was side-lined as it was 'not sensational' like AIDS. In his outgoing presidential report for the NZSSD, Beaven criticised the government's prioritisation of funds to AIDS when diabetes would annually kill '1000 times' more people than AIDS would over several years.⁹⁸

Rather than focusing on inadequate funding, the NZSSD took a new approach to government in April 1985: a request for 'a government-directed review of diabetes services available in this country'.⁹⁹ Dr Peter Dunn, a Waikato diabetes specialist who trained under Beaven, submitted to Bassett this request with supporting studies of hospital admission data on diabetes from Christchurch, Auckland and Waikato. This data showed that people with diabetes had higher hospitalisation rates and longer duration stays than those without the disorder; unrecorded and undiagnosed diabetes in hospital data, however, meant 'the extent of

⁹⁶ Deborah Mary Jowitt, 'Government Policy Relating to Hepatitis B in New Zealand 1970–2005', PhD thesis, University of Auckland, 2008, pp.125–6.

⁹⁷ *Ibid.* pp.126–7.

⁹⁸ D.W. Beaven, 'NZSSD President's Report 1984–85', p.2.

⁹⁹ Dunn to Bassett, 3 April 1985.

this public health problem is underestimated'.¹⁰⁰ Additionally, while acute complications were less common, the expensive chronic complications of the vascular system and kidneys treated in hospitals had risen steadily over several decades. The submission also reported on studies that indicated that better organised care and education could reduce hospital costs. Indeed, Dunn emphasised that the NZSSD 'did not see the expensive expansion of hospital beds as being a solution to the problem': 'We believe there is now a need for guidelines on the appropriate dietary, educational, podiatric, ophthalmologic, general medical, vascular and orthopaedic services which should be available to support community-based systematic care of diabetic subjects'.¹⁰¹

The government's response to the submission was favourable. The Acting Minister of Health requested that Dunn, now NZSSD president, meet with health officials in Wellington to discuss collaboration on a survey of diabetes services.¹⁰² Dunn met with the Director-General of Health, Dr Ron Barker, and other senior administrators who determined that the NZSSD Executive should produce a questionnaire to circulate to hospital boards. The survey results would be passed to the Hospitals Advisory Committee with a recommendation for it to review diabetes services. The survey and review would potentially contribute to a service development plan for diabetes.¹⁰³ In March 1986 Dr George Salmond, who was about to replace Barker as Director-General, met again with Dunn and suggested a new collaboration: the NZSSD and Department should jointly apply to the MRC for funding of a broader research project assessing the use, availability and consumer preferences for diabetes services. Salmond was on the MRC's Forward Planning Committee, which set research funding priorities. He knew a proposal that could have immediate relevance to the utilisation and cost-

¹⁰⁰ Ibid.

¹⁰¹ Ibid.

¹⁰² Acting Minister of Health to Dunn, May 1985, ABQU 632 W4452 667/ 131-20 (60257), ANZW.

¹⁰³ R. Barker, 'Notes on meeting with Dunn', 31 May 1985, ABQU 632 W4452 667/ 131-20 (60257), ANZW.

effectiveness of community-based services would be attractive to the government when the MRC applied for a supplementary funding grant. While investigating this option the NZSSD, already having developed the hospital survey, decided to pursue it independently as a tool ‘for future advocacy’.¹⁰⁴

In the meantime, the NZSSD had successfully established a review of diabetes services as a policy concern for the Health Department. In mid-1986, the Department’s Hospitals Division signalled it would establish a working committee for diabetes service planning guidelines to hospital boards. Following a shift from essentially demand-based to population-based funding for hospital boards in 1983, the Department used service-planning guidelines in a number of other areas to help boards allocate their resources.¹⁰⁵ The NZSSD lobbied for its representatives to be included on the diabetes working committee and for it to be in operation by the end of the year.¹⁰⁶ In late 1986 Salmond appointed Beaven to chair the committee, made up mostly of NZSSD members, and its hospital survey results became a starting point for the guidelines’ recommendations.¹⁰⁷ These guidelines, however, would be aimed at area health boards, not hospital boards.

The government’s major health policy preoccupation in the 1980s was the transition from hospital boards to area health boards. Labour had first mooted the concept of AHBs – elected regional authorities that administered both hospital and public health services – in the 1970s

¹⁰⁴ *NZSSD Newsletter*, 26, 1986, p.1.

¹⁰⁵ AJHR, E10, 1985, p.41. The shift towards ‘service planning’, as opposed to hospital design, in resource allocation had its roots in the 1970s, particularly under the North Canterbury Hospital Board (of which Beaven was a member): see Deborah Salter, ‘The “Ugly Sister of Welfare”: the idea of health care ‘rationing’ in New Zealand, 1968–c.1980, MA thesis, Victoria University of Wellington, 2011, pp.36–39.

¹⁰⁶ *NZSSD Newsletter*, 17 September 1986, p.1.

¹⁰⁷ Beaven to Salmond, 23 March 1989, D.W. Beaven Papers, Accession #195, 36825, MBL; *NZSSD Newsletter*, 30 June 1987. The guidelines working party consisted of dietitian Sue Pollard, endocrinologist Dr Peter Dunn, diabetes nurse specialist Margaret Llewellyn, physician Dr Ian McPherson, diabetes nurse educator Anne Waterman, Acting General Manager of the Nelson Area Health Board A.J. Cooke and E. Marie Wilson, a secretary with the Department of Health.

to achieve better local democracy and integrated service planning. In 1983, the National government introduced the Area Health Board Act, which allowed hospital boards to voluntarily transform into AHBs. After the uncertainty about whether there would be market-oriented restructuring of the health sector in Labour's first term (1984–87), when David Caygill became Minister of Health in 1988 he decided to continue with the establishment of AHBs.¹⁰⁸ That same year, the State Sector Act introduced managerial principles into government agencies, including those in the health system, which were intended to improve their efficiency and accountability. In 1989, another new Minister of Health, Helen Clark, legislated for the remaining hospital boards to become AHBs by the time of the local body elections that year. Clark also introduced new mechanisms that she intended to support a preventive focus for the health sector: the New Zealand Health Charter defined ten public health goals and targets that AHBs were contractually obliged to work towards achieving.¹⁰⁹

Released in the midst of these structural changes at the end of 1988, the Health Department's diabetes service planning guidelines for AHBs, *Diabetes Mellitus: A Model for Health Maintenance*, emphasised a preventive and 'shared care' approach to diabetes. This approach meant AHBs needed to plan services, and establish mechanisms through which the person with diabetes, primary care providers and specialist multidisciplinary teams, could work together to prevent, detect and intervene early in complications to avoid hospitalisation. This was a formulation of the patient self-sufficiency ideal Beaven advocated 'as a positive concept' of consumer empowerment that illustrated 'practical health maintenance and disease prevention'. Since the 1970s, Beaven had argued that diabetes was a model condition for reorganising the health system from services to treat disease to those that improve health; if services supported people with diabetes to keep their blood sugars (and lipids and blood

¹⁰⁸ Gauld, p.62.

¹⁰⁹ Ibid., pp 64–65.

pressure) normal they did not get sick and require expensive hospital treatment.¹¹⁰ In addition to specifying staffing levels and organisation, the guidelines recommended prevention of NIDDM in conjunction with other “‘life-style” disorders’ through developing ‘a package to promote healthy and active living targeted at those at risk’. These programmes were to include nutrition guidelines, non-smoking education, appropriate exercise, improved self-esteem and self-determination, and raising awareness to improve early detection.¹¹¹

The service planning guidelines aligned with the government’s new public health agenda. Beaven wrote to Clark after her announcement of the Health Charter that he was ‘delighted’ with her approach which he believed mirrored that of the service planning guidelines.¹¹² The goals, in part, reflected an international movement established with the WHO’s 1978 ‘Health for All by the year 2000’ campaign, which urged national governments towards target setting and monitoring for disease reduction.¹¹³ Although not an immediate priority, one of Clark’s public health goals for AHBs was to reduce nutrition-related disorders, which included NIDDM. Goals to reduce smoking, high blood pressure and coronary heart disease, and stroke could positively affect diabetes long-term complications.¹¹⁴ Clark met with the new presidents of the NZSSD and the DANZ, Dr Ian McPherson and Lee McLeod, in July 1990 to discuss the implementation of the service planning guidelines and ‘a case for further targeting of the adult-onset variety of diabetes’. After this meeting, Clark directed AHBs to provide the

¹¹⁰ Beaven to Minister of Health, 17 October 1988, Primary Health Care – Diabetes, 1986-90, ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW. See also Chapter Four.

¹¹¹ D.W. Beaven and Dorothy Neal, eds, *Diabetes Mellitus: A Model for Health Maintenance: Service Planning Guidelines for Area Health Boards*, Wellington, 1988, pp.33, 36.

¹¹² Beaven to Clark, 14 April 1989, ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW.

¹¹³ This approach would come to encompass diabetes specifically in the 1990s: see Chapter Seven. In relation to the connections between these international trends, elite professionals and government bodies in British diabetes policy development, see Martin Moore, ‘A Question of Control? Managing Diabetes and its Professionals in Britain, 1910–1994, PhD thesis, University of Warwick, 2014, pp.319–32. Another important element arising from ‘Health for All’ was a focus on community development; this is discussed in Chapter Seven of this thesis. On the development of Clark’s goals, see Robert Beaglehole and Peter Davis, ‘Setting national health goals and targets in the context of a fiscal crisis: the politics of social choice in New Zealand’, *International Journal of Health Services*, 22, 3, 1992, pp.417–28.

¹¹⁴ For the list of goals and priorities see, Beaglehole and Davis.

Department of Health with a statement on their policy regarding diabetes, including the ‘identification of high risk [sic] groups and planned interventions’.¹¹⁵ She requested that both the lay and professional diabetes groups continue to work closely with AHBs and the Department.¹¹⁶ The apparent success of this engagement with politicians in the 1980s gave diabetes organisations confidence to become more active participants in policy processes, while also suggesting a significant new emphasis on the high risk and NIDDM rather than diabetes as a whole.

The NZSSD and the MRC Diabetes Task Force

Medical research funding was another area of health policy facing review and uncertainty in the late 1980s. The NZSSD’s work in establishing a case for investment in diabetes research traversed the conflicting agendas of government departments and achieved unanticipated results.

In September 1983, Beaven approached the MRC’s Forward Planning Committee to consider diabetes as a priority research area. He questioned the Committee’s recent prioritising of respiratory diseases when diabetes was ‘almost universal’ in the Polynesian population, contributed to 10 per cent of all hospital bed day stays and when New Zealand had only two physicians specifically trained as diabetes specialists (other specialists were general physicians with an interest in diabetes).¹¹⁷ While the Committee largely agreed with the case Beaven put forward, it decided that the existing priority areas of health services research and the health of Polynesian populations could adequately encompass diabetes.¹¹⁸

¹¹⁵ Helen Clark to David Butcher (MP for Hastings), n.d. ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW.

¹¹⁶ Clark to McLeod, 1 August 1990, ABQU 632 W4452 1840/ 358-60-4 (68648), ANZW.

¹¹⁷ Beaven to Hodge, 26 September 1983, Forward Planning Committee General Correspondence, YCBN 5990 3b 11/1/3 part 2, Archives New Zealand, Auckland (ANZA). By ‘almost universal’, he meant that a case of diabetes could be found in almost all extended families of Pacific descent.

¹¹⁸ Borrows to Beaven, 8 March 1984, YCBN 5990 3b 11/1/3 part 2, ANZA.

However, it appears Beaven did influence the Forward Planning Committee to look more closely at specific funding for diabetes research. Beaven's colleague at Princess Margaret Hospital, endocrinologist Professor Eric Espiner, was on a sub-committee set up in March 1984 to review the MRC's triennial application for government funding. This sub-committee added diabetes to the application as one of the priority areas that required new funding in 1985–87.¹¹⁹ The application included details from Beaven and Dr Russell Scott's (a MRC research fellow) studies of hospital utilisation in Christchurch, which showed people with diabetes admitted to hospital, for whatever reason, stayed ten days more than those without the disorder. Extrapolated out, this finding suggested New Zealand was spending approximately an extra \$15 million per year hospitalising people with diabetes. The Council felt the subcommittee's request for \$300,000 for 'research towards improved techniques of management and education in diabetics' was thus more than justified.¹²⁰ Due to the snap election in July 1984, the application, originally intended for National's Minister of Health was submitted in August to Labour's Michael Bassett.

Despite a warning from the Director-General of Health that the new Labour administration saw new spending as impossible, the MRC did not reduce the funding it sought and faced a clash with Treasury.¹²¹ In its triennial application, the Council argued it could neither maintain support for current project numbers nor initiate new programmes in areas 'vital to New Zealand's interest' without 'a significant forward step in funding' as there had been no real growth in funding since the mid-1970s.¹²² The number of funding applications had

¹¹⁹ The sub-committee had the power to co-opt experts to add projects to the application and handwritten undated notes from a sub-committee meeting suggest that Espiner pushed for the inclusion of diabetes after having consulted with Beaven: see 1985–87 Triennium Grant Application, 1984–86, YCBN 5991 Box 2 f, ANZA.

¹²⁰ 1985–87 Triennium Application, p.22, Forward Planning Committee – Triennial Application, 1985–87, YCBN 5990 2/a 11/2 part 1, ANZA.

¹²¹ J.V. Hodge, Notes on Telephone Discussion with Dr R.A Barker, 3 August 1984, Forward Planning Committee: Triennial Application 1985–87, YCBN 5990 3a 11/2 part 2, ANZA.

¹²² Triennial Application for Funding 1985–87, p.1, Forward Planning Committee: Treasury visit to MRC 1984, YCBN 5990 Box 1a 11/2, ANZA.

steadily risen and applicants sought larger sums, which the MRC attributed to the increased numbers of highly trained medical scientists and technological developments. It thus requested approximately 10 per cent more than its current grant.¹²³

After the application reached the hands of Treasury officials in September 1984, it became clear that the MRC faced a major battle to achieve this increase. Treasury and Health Department officials met with MRC representatives in November to discuss the application before formulating their own recommendations to Cabinet. In arranging the meeting, the Deputy Director-General of Health, Dr George Salmond, suggested to the MRC Director, Jim Hodge, that he should prepare a paper to structure their discussions. Salmond explained that the Treasury officials would come to the meeting ready to preach ‘the dogma ... [of] the “free market” model’.¹²⁴ Although the MRC put up a reasoned case as to why medical research, which rarely produced a marketable commodity, could not be treated like research and development in industry, it did little to sway the Treasury’s perception that medical research ‘outputs’ were similar to those of a steel mill.¹²⁵ Treasury officials opposed any new funds as they argued New Zealand could just import more research, seemingly unconvinced by arguments that there was a need for local expertise to implement it. Moreover, they saw the Council’s priority setting process as reflective of the interests of available scientists rather than the need to address national problems. As MRC Secretary J.A. Borrows put it, ‘In essence, they [Treasury officials] wished to know what difference the many millions of dollars spent on research was making to the practice of clinical medicine or the health service in New Zealand.’¹²⁶

¹²³ Ibid.

¹²⁴ Salmond to Hodge, 31 October 1984, YCBN 5990 Box 1a 11/2, ANZA.

¹²⁵ Notes on a Meeting with Treasury and Health Department Officials, 13 November 1984, YCBN 5990 Box 1a 11/2, ANZA.

¹²⁶ Notes of a Meeting with Health Department Officials, 14 February 1985, p.2, YCBN 5990 Box 1a 11/2, ANZA.

Treasury officials' attitudes signalled that scientific value was not enough to justify public funding of medical research; it also had to have cost benefits to government. The Health Department supported extra funding, but it also wanted to encourage more research that would directly lead to improved health services. Cabinet followed Treasury's advice to maintain MRC funding for the next triennium at current levels, but also gave it the opportunity to apply for supplementary grants, on an annual basis, for priority issues where it could demonstrate economic benefits. Salmond saw Cabinet's acceptance of the argument that 'compensatory savings', such as those from reduced hospitalisations, could flow from investment in health research as a considerable achievement in the wake of the strong sway Treasury officials had with government.¹²⁷ The Forward Planning Committee met in March 1985 and decided to approach people it 'considered capable' to develop research proposals in four priority areas from the original triennial funding application. The Committee corresponded with Beaven and the NZSSD Executive, and by June the reconvened triennial subcommittee agreed for Espiner to oversee the development of a diabetes proposal with the NZSSD President Dr Peter Dunn and colleagues.¹²⁸

The diabetes proposal was not ready in time for the 1986 funding round, but the MRC gave Espiner and the NZSSD another chance for the next funding round. In early 1986, Dunn and NZSSD Secretary Rick Cutfield met with Hodge who informed them that if the MRC received further supplementary funding for 1987, the Forward Planning Committee had determined it should all go towards diabetes research.¹²⁹ The NZSSD sought submissions from members and developed an overview of diabetes research needs. Borrows edited the

¹²⁷ Minutes of a Meeting of the Forward Planning Committee, 12 March 1985, p.4, Forward Planning Committee Minutes, 1976–88, YCBN 5990 Box 4c 11/1/1, ANZA.

¹²⁸ Minutes of a Meeting of the Forward Planning Committee Sub-Committee on Priority Research Development, 20 June 1985, p.1, YCBN 5990 Box 4c 11/1/1, ANZA.

¹²⁹ *NZSSD Newsletter*, 26, 1986.

proposal and presented it to Council at its November meeting.¹³⁰ The proposal called diabetes ‘a major public health problem ... [and] a major drain on health resources’ and recommended four areas to focus on: epidemiology, delivery of health care services, special clinical projects and basic science, and workforce strengthening.¹³¹

The supplementary funding application did not fit with the Health Department’s view of research priorities for diabetes. The application requested \$650,000, of which \$150,000 would go to epidemiology, \$100,000 to health services, \$450,000 to basic science and clinical projects and \$150,000 to workforce strengthening.¹³² The MRC consulted with the Health Department prior to submitting the application to the Minister of Health. Dr Judith Johnston, who was the Director of the Department’s Health Services Research Development Unit, commented that it was, ‘Not a good case for diabetes research’ as research needed to be ‘change directed and policy driven, not just information oriented’.¹³³ She questioned the allocation of funds to each area: ‘so much money has already been invested and there is a lot to show for it in a clinical sense, but not a lot in terms of services in different areas or in terms of community awareness’.¹³⁴ Johnston’s comments suggest a degree of realism about the low likelihood of Cabinet granting the requested amount, but also reflected the Department’s position that the MRC generally needed to increase its support for research into health services.

Espiner rebutted Johnston’s criticisms at a MRC meeting by pointing out that ‘while he appreciated the need to highlight health service priorities ... funding was required at several

¹³⁰ Borrows to Cutfield, 10 October 1986, Diabetes Task Force Committee General Correspondence, 1985–90, YCBN 5981 8/a, ANZA.

¹³¹ Hodge to Bassett, 22 December 1986 YCBN, 5990 22d 11/6/7, ANZA.

¹³² Ibid.

¹³³ Director HSRDU to Director-General of Health, 3 November 1986, YCBN 5981 8/a, ANZA.

¹³⁴ Ibid.

levels to get the best value for money'.¹³⁵ Both the MRC and the NZSSD were cognisant of, and agreed with, the Department's desire for a focus on community-based care delivery, but had prioritised the lack of up-to-date basic epidemiological data, which they believed necessary to evaluate the effectiveness of any interventions.¹³⁶ Moreover, with only a small diabetes research community in New Zealand the MRC believed it prudent to support existing projects while it attempted to strengthen the research workforce. The Council recognised 'the right of the Department to see one part of the package as more important than the other', but 'in order to make an impact' it would continue to seek a large sum of funding.¹³⁷ The revised document, sent to Bassett in December 1986, made it clearer how basic science research was fundamental to developing better management of diabetes and that the Council was willing to select a lesser number of projects in consultation with the Health Department.¹³⁸ By not fitting with the Health Department's perceptions of diabetes research needs, however, the application failed.¹³⁹

The conflicting opinion between the Health Department and MRC on diabetes research was part of a wider debate over the funding of health research. At the MRC's golden jubilee symposium in November 1987, Salmond, now Director-General of Health, issued a challenge for the MRC to review its priorities. Although the MRC argued it had been 'actively trying to enlarge its portfolio of research' in public health and social medicine for over a decade, it still only accounted for 11 per cent of expenditure.¹⁴⁰ The MRC was concerned that if it were to fund more non-medical research, without an increase in government funding, current research

¹³⁵ Minutes of a Meeting of the MRC, 24–25 November 1986, p.13, MRC Minutes 1983-87, YCBN 5804 Box 6a, ANZA.

¹³⁶ Minutes of the Annual General Meeting of the NZSSD, 20 May 1986, Personal Collection of Dr Bob Smith; Minutes of the Inaugural Meeting of the Diabetes Task Force, 30 September 1987, Diabetes Task Force Minutes 18 February 1988, YCBN 5805 1/C, ANZA.

¹³⁷ Minutes of a Meeting of the MRC, 24–25 November 1986, p.13.

¹³⁸ Hodge to Bassett, 22 December 1986.

¹³⁹ Salmond to Hodge, 24 August 1987, YCBN, 5990 22d 11/6/7, ANZA.

¹⁴⁰ Medical Research Council, *A Health Research Council (a discussion paper)*, June 1988, p.1.

programmes would suffer. The Health Department was also undertaking major restructuring to prepare it to focus more on policy and withdraw from operational activities, leaving the future of its research units in doubt.¹⁴¹

Following the MRC application for its triennial grant in early 1988, officials requested a government review of the level and mix of biomedical and public health research, procedures for assigning funds, and the relationship between research and policy. A concurrent review into government-funded research in science and technology indicated the government might subsume medical research into a broader funding agency. Cabinet announced a review of all publicly funded health research in September 1988. This review recommended that government retain its responsibility for funding health research through a separate institution, but with distinct, contestable budgets for biomedical and public health areas.¹⁴² This led to the formation of the Health Research Council in 1990. In the intervening eighteen months, however, with its future in question, the MRC could not make long-term commitments to new projects, which left researchers with considerable uncertainty and a lack of funding.¹⁴³

Diabetes research escaped some of this uncertainty as the MRC, even before learning the result of the supplementary funding application, decided that the NZSSD had demonstrated enough to warrant establishing a Diabetes Task Force. Although the MRC did not receive an official rejection of its application until August 1987, there were early indications it would fail.¹⁴⁴ At the May 1987 meeting of Council Borrows recommended that some of an unexpected surplus in the Council's accumulated funds should go towards a diabetes research

¹⁴¹ David Stewart, Bernie McKay and Claudia Scott, *Research for Health: Report of the Review of the Organisation and Public Funding of Biomedical and Health Systems Research in New Zealand*, May 1989, Wellington, p.3.

¹⁴² *Ibid.*, pp.1–2, 59–69.

¹⁴³ J.V. Hodge to Prof D.W. Beaven, 17 October 1989, D.W. Beaven Papers, Accession #195, 36805, MBL.

¹⁴⁴ Minutes of a Meeting of the Forward Planning Committee, 7 April 1987, p.3, YCBN 5990 4c 11/1/11, ANZA.

fund. The Council agreed on ‘the need to show a commitment to the diabetes area given the submission on it’ and appointed Espiner to convene a Diabetes Task Force which would oversee \$300,000 of dedicated diabetes research funding.¹⁴⁵

The Diabetes Task Force, which the MRC modelled after an earlier one established for asthma, co-ordinated research that would have a long-term effect on diabetes policy and services. Espiner and Borrows co-opted Cutfield, Scott and Dr John Baker (a biochemist at Green Lane Hospital) to the Task Force, which held its inaugural meeting in September 1987. The Task Force went on to co-opt epidemiologist Dr Robert Scragg, and Dr Jim Mann, a clinician with an interest in nutrition. It defined its priority areas for research, in order of importance, as epidemiology, diabetes in special groups (the elderly and Polynesians), development of a diabetes register and health services research. Additionally, it recommended the establishment of two research-training fellowships.¹⁴⁶ The Task Force provided supplementary grants and personally supported some researchers, but mainly worked by directing projects through the Council’s competitive assessing procedures. For the three-year duration of the Task Force, the MRC designated diabetes a priority area for all applications to Council for funding and training fellowships.¹⁴⁷ These initiatives played a vital role in expanding the diabetes research workforce, establishing new research projects and providing an evidentiary base for policy development in the 1990s.¹⁴⁸

¹⁴⁵ Minutes of a Meeting of the MRC, 26–27 May 1987, p.4, MRC Minutes 1983–87, YCBN 5804 Box 6a, ANZA.

¹⁴⁶ ‘Priorities of the MRC Task Force on Diabetes Mellitus and its Complications’, Diabetes Task Force Committee General Correspondence, 1987, YCBN 5981 7/a, ANZA.

¹⁴⁷ Minutes of a Meeting of the Forward Planning Committee, 10 June 1988, p.8, YCBN 5990 Box 4c 11/1/1, ANZA.

¹⁴⁸ Report of the MRC Task Force on Diabetes Mellitus and its Complications to the MRC, 1990, Diabetes Task Force Committee General Correspondence, 1985–90, YCBN 5981 8/a, ANZA.

Thus, the NZSSD had an important role in securing government funds for diabetes research and the establishment of a Diabetes Task Force. This funding was less than half of the amount the NZSSD had hoped for, but considering the general research funding restrictions and the lack of Treasury and Health Department support, it was a significant indication of the influence of advocacy, spearheaded by Beaven, in determining policy outside of budgetary processes.¹⁴⁹

Conclusion

In his outgoing president's report for 1987, Dr Peter Dunn reflected on the roles of the NZSSD. Not only did it organise conferences and support health professional collaboration but, 'in this country where diabetes mellitus is common and the health resources available to combat it are so meagre, it has another major task, a political one, to act as an advocate to government and its institutions to gain the appropriate financial resources'.¹⁵⁰ Dunn acknowledged Professor Beaven as 'the driving force behind many of our recent gains in this area'.¹⁵¹

Beaven, diabetes self-described 'ageing activist', emerged as the key figure to politicise diabetes in the 1980s.¹⁵² He believed that New Zealand needed to keep up with the United States in the race to combat diabetes, particularly as diabetes became a major problem in the Pacific. His influence appeared in the form and content of all the major diabetes organisations' publicity and political lobbying in this decade: diabetes organisations used the media and acted at a national level to a much greater extent than previously, as they attempted

¹⁴⁹ Political scholars and historian and former Minister of Health, Michael Bassett, have explained how budgetary processes can be an indication of government priorities and the relative influence of pressure groups: Jowitt, p.25, and Michael Bassett, *Working with David: Inside the Lange Cabinet*, Auckland, 2008.

¹⁵⁰ Peter Dunn, 'NZSSD President's Report for 1987', D.W. Beaven Papers, Accession #195, 36810, MBL.

¹⁵¹ *Ibid.*

¹⁵² Davidson to Beaven, 17 January 1979.

to demonstrate diabetes was the ‘health problem for the 1980s’.¹⁵³ Diabetes organisations were self-consciously aware of the need to project a united image and cohesive message to stand out against a proliferation of other health organisations and government attention to ‘more fashionable’ or feared diseases.¹⁵⁴ Yet, internal disunity remained a problem for diabetes advocacy and often the behind-the-scenes activity of the NZSSD was just as important for generating ‘gains’ for diabetes.

Equally, the NZSSD’s ‘gains’ partly reflected its ability to match its advocacy to the policy objectives of government and its agencies at a time when these were continually under review. Appealing to a government highly concerned with transforming the poorly performing economy, the NZSSD argued that investment in diabetes research was a cost-efficient exercise. Lack of support from senior Health Department officials and Treasury scepticism, however, contributed to the Minister of Health rejecting an NZSSD/MRC application for supplementary funding for diabetes research. The government wanted research that could immediately improve health services whereas the NZSSD saw an up-to-date epidemiological picture and clinical understanding of diabetes as necessary first steps to achieve this improvement. The MRC, however, on the strength of the NZSSD’s submission, and perhaps feeling threatened in regards to its own survival, established the Diabetes Task Force and allocated specific funds to promote diabetes research. Following the NZSSD’s request for a government-directed review of diabetes services, the Health Department appointed Beaven to chair a working party, made up mostly of NZSSD members, to formulate diabetes service planning guidelines. While not having assured funding or implementation, the guidelines differed little from the earlier plans Beaven had formulated, but it was the

¹⁵³ NZDF, ‘Diabetes in New Zealand: A Health Problem for the 1980s’.

¹⁵⁴ D.W. Beaven, ‘NZSSD President Report’, 1984.

interventions for NIDDM in high-risk groups which became a focus as Helen Clark set new goals for the health system.

Sociologist Steven Epstein has proposed looking beyond just policy outcomes as the measure of success of health advocacy: ‘At times health advocacy may bring about unanticipated changes ... or establish a path that subsequent health advocates may head.’¹⁵⁵ Some of the most important effects of diabetes advocacy efforts would come to fruition in the next decade. By starting to create an image of diabetes as a costly and serious health problem, and informing politicians how these costs could be reduced, diabetes organisations built a foundation from which they could move diabetes up the policy agenda of the more aggressively cost-cutting National government of the 1990s. Their single-issue advocacy, however, hid tensions around the priorities accorded to different parts of the diabetes problem. These tensions would also become more apparent, despite an increasing focus on an integrated approach to diabetes management. The next chapter thus considers the rise of diabetes as a public health policy priority and some of those tensions.

¹⁵⁵ Epstein, p.269.

CHAPTER SIX

‘The challenge is how to ... manage this disease in the new health environment’: diabetes policy in the 1990s

Regional Health Authorities will increasingly look to contract for services with community groups ... to deliver the necessary prevention and education messages to “at risk” communities. This then is the challenge for community organisations like Diabetes New Zealand. You may want to consider how you might fit into the health environment... The challenge is how to improve our ability to manage this disease in the new health environment.¹

The National government’s Associate Health Minister, Katherine O’Regan’s challenge to Diabetes New Zealand (DNZ) at its 1994 annual conference invites a number of questions about the visibility of diabetes as a policy issue in the 1990s. What exactly was the ‘new health environment’ and how would diabetes organisations respond to it? What challenges, and what opportunities, did the ‘new health environment’ bring to managing diabetes? This chapter explores these questions in order to uncover how, despite a government determined to cut back on health expenditure generally, a government-funded plan came about to address diabetes as a national public health problem.

Government social policy and ‘the new health environment’ 1990–1996

The 1990s were a tumultuous period for health services and social policy in New Zealand. Expanding on the fourth Labour government’s policy direction of the late 1980s, the National government that came to power in November 1990 quickly set out an agenda to cut welfare spending and reform the health system. There were both economic and ideological reasons guiding government actions.

¹ Katherine O’Regan, ‘A challenge by the Honourable Katherine O’Regan to DNZ’, (transcript of speech to conference), *Breakthrough*, 8, 2, Winter 1994, p.11.

The fourth Labour government (1984–1990) had set a new direction for the New Zealand economy and social policy. As touched on in the last chapter, the government responded to the fiscal crisis it faced on entering office with major economic reforms. These reforms, which became known as ‘Rogernomics’ after the Minister of Finance Roger Douglas, rapidly turned one of the most highly regulated economies in the world to one of the least regulated.² Douglas supported the neoliberal ideas of American economist Milton Friedman, Treasury advisers and other Western governments, namely that of Ronald Reagan in the United States and Margaret Thatcher in Britain. Under the neoliberal economic model, the state provision of public services was problematic as it diminished consumer choice and thus the incentives to improve service quality; contestability would encourage services that were more responsive to consumer needs.³ Contestability also offered a means to address concurrent Maori and feminist calls for a less paternalistic, monolithic and disempowering welfare state.⁴ Labour began to move away from its former ideals of universality towards targeted welfare, contracting out services, and capping government spending. Nevertheless, rising unemployment following deregulation and the 1987 stock market crash thwarted the latter goal and Labour left office with an even higher budget deficit.⁵

The National government (1990–1996) introduced dramatic changes to the welfare system to address unemployment. Almost immediately on entering office, the Finance Minister Ruth Richardson set out a co-ordinated reform programme for the labour market and social welfare.⁶ Neoliberal ideology sat more comfortably with the centre-right National government

² Margaret McClure, *A Civilised Community: A History of Social Security in New Zealand, 1898–1998*, Auckland, 1998, p.211.

³ Christine Cheyne, Mike O’Brien and Michael Belgrave, *Social Policy in Aotearoa New Zealand: A Critical Introduction*, Auckland, 2000, pp.79–82.

⁴ Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government, and Welfare in New Zealand, 1840-2005*, Wellington, 2007, pp.193–4.

⁵ McClure, pp.222, 232.

⁶ *Ibid.*, p.234.

and the July 1991 budget drastically cut social spending to what the Minister of Social Welfare, Jenny Shipley, described as a ‘modest safety net’ for those in ‘genuine need’.⁷ National extended Labour’s targeted approach to welfare and introduced policies ensuring minimal assistance levels it believed would make work on a minimum wage more attractive to people on benefits. Richardson and Shipley espoused a morality-laden argument for the welfare reforms: they wanted to restore an ideal of active citizenship centred on personal and family responsibility and a strong work ethic. In their view, the welfare state had destroyed these values and replaced them with a culture of ‘dependency’ and a growing underclass.⁸

Alongside the welfare reforms, National introduced market-oriented restructuring of the health system. In 1988, the Labour government’s Taskforce on Hospitals and Related Services had recommended introducing a competitive market in health care delivery through splitting the government’s purchaser and provider roles.⁹ The government did not adopt this recommendation at the time but National did. The July 1991 budget included plans to abolish the fourteen majority elected area health boards and replace them with four Regional Health Authorities (RHAs). The RHAs would purchase personal health services from the former public hospitals (now twenty-three profit-driven Crown Health Enterprises (CHEs)), private and community providers. A National Advisory Committee on Core Health Services would define the principal services RHAs were to purchase, and who was entitled to them. A separate Public Health Commission (PHC) would provide policy advice and purchase public health services from a ring-fenced allocation in Vote Health. The Department of Health was to become a Ministry with monitoring and policy functions.

⁷ Jenny Shipley, *Social Assistance: Welfare that Works: A Statement of Government Policy on Social Assistance*, Wellington, 1991, p.13.

⁸ McClure, pp.232–4.

⁹ Alan Gibbs, *Unshackling the Hospitals: Report of the Hospital and Related Services Taskforce*, Wellington, 1988.

The government believed the new system, to come into effect in July 1993, would be more efficient, innovative, responsive to individual needs, and progress the longer-standing policy goal to de-emphasise hospitals in favour of prevention and community care.¹⁰ Moreover, as the Associate Health Minister Maurice Williamson argued in 1992, ‘the Government’s view had always been that individuals are responsible for their own health’ and that the reforms were necessary as ‘many people have [wrongly] felt for many, many years they have a right to free access to health’.¹¹ User part-charges and means testing to target services to only those deemed most in need reflected this view.

The ethical questions involved in deciding what constituted a core service, restrictions on health spending, user pays and targeted social assistance made the reforms highly contentious.¹² For those affected, these policies seemed to run counter to long-held expectations of the role of the state in welfare provision while most New Zealanders, regardless of their socio-economic status, saw free access to health care as a fundamental right of citizenship.¹³ Although the government did make some policy reversals and adjustments in response to public pressure, its overall ideological position and budgetary stringency did not change significantly over its first two terms in office.

‘I have no idea how my family will cope’

In February 1991, the Leader of the Opposition Mike Moore read out a letter in parliament from one of his constituents. The constituent was on a benefit and had a nine-year-old

¹⁰ Toni Ashton, ‘The Health Reforms: to Market and Back?’, in Jonathan Boston, Paul Dalziel and Susan St John, eds, *Redesigning the Welfare State in New Zealand: Problems, Policies, Prospects*, Auckland, 1999, p.135; Cheyne, O’Brien and Belgrave, p.218.

¹¹ Minutes of the Annual General Meeting of DNZ, 12 April 1992, pp.1–2, Diabetes New Zealand, Wellington (DNZ).

¹² Robin Gauld, *Revolving Doors: New Zealand’s Health Reforms*, Wellington, 2001, pp.96–100, 85.

¹³ McClure, p.238; Omar Hamed, ‘Resistance to Neo-Liberalism in New Zealand: An Analysis of Three Campaigns Against User Pays and Privatisation’, MA thesis, University of Auckland, 2013, p.43.

daughter with diabetes. After the looming benefit cuts she would have a weekly income deficit of \$119. As this did not take into account price rises on health services for her daughter, she concluded, 'I have no idea how my family will cope'.¹⁴ While this woman's concerns were useful for Moore's political argument, they represented wider unease amongst people with diabetes, their families and health professionals that aspects of the welfare and health reforms would have negative implications for people with diabetes.

A major policy change to affect people with diabetes was the redefinition of what constituted a chronic disease and thus the subsidised health care they were entitled to receive. People carrying a chronic disease certificate were eligible for extra subsidies for general practitioner and prescription charges. The Health Department revised the eligibility criteria for the chronic disease certificate in 1988 to include only 'those patients requiring frequent and regular treatment and suffering from a chronic condition of sufficient severity to be disabling or debilitating'.¹⁵ This severity requirement meant that all people with diabetes no longer automatically qualified for the certificate. A woman affected by this change wrote to the then Labour Minister of Health David Caygill with her concern the policy was politically, rather than medically, motivated. She argued any doctor could tell him diabetes was a chronic condition and that Southern Cross insurance would not pay her medical fees because they also defined it as such.¹⁶

Once Labour was in opposition in the early 1990s, it criticised the National government for creating further costs for people with diabetes. Moore accused the government of misleading voters in its election promise that, 'The safety net system for prescription charges will be

¹⁴ *New Zealand Parliamentary Debates* (NZPD), 19 February 1991, p.92.

¹⁵ David Caygill to Shirley Thomson, 20 December 1988, Primary Health Care – Diabetes, 1986–90, ABQU 632 W4452 1841 358-60-4 (68648), Archives New Zealand, Wellington (ANZW).

¹⁶ Shirley Thomson to David Caygill, 1 November 1988, ABQU 632 W4452 1841 358-60-4 (68648), ANZW.

improved so that people in need will have ready access to pharmaceuticals.¹⁷ Instead, he noted, National had increased prescription charges for children and beneficiaries from \$2 to \$5 an item and for adults from \$5 to \$15. Labour Member of Parliament (MP) Geoff Braybrooke, who had insulin-dependent diabetes (IDDM) himself, also spoke in parliament on the financial difficulties of parents of children with diabetes. He stated that people with diabetes were entitled to twenty-five needles free per month, but the average child needed ninety. Furthermore, the government gave no subsidies on the more expensive, though more user-friendly, pen needles. National had scrapped the chronic disease certificate altogether and Braybrooke was emphatic in his opinion, ‘the government says diabetes is not a chronic disease. If it is not a chronic disease, I want to know what the hell is?’¹⁸

Many people with diabetes took a personal affront to the apparent undermining of the seriousness of their condition. Individuals and diabetes societies bombarded the Minister and Associate Ministers of Health with letters that accused the government of violating a World Health Organization (WHO) ruling that diabetes was a serious chronic disease.¹⁹ The letters increased in late 1991 as people with diabetes learned the government had removed a blood glucose test from the free laboratory schedule. Writing in a language they presumed the government would understand, complainants stressed the poor economic judgement of the government’s policies; they asserted that people with diabetes who had regular doctor’s visits, monitoring tests and intensive treatment were less likely to end up hospitalised with far more costly complications. Under mounting pressure, the Ministers responded they had a more effective way of targeting services to people with diabetes.

¹⁷ NZPD, 19 February 1991, p.92.

¹⁸ NZPD, 30 July 1992, p.10,228.

¹⁹ Most letters are in Primary Health Care – Diabetes, 1991–92, ABQU 632 W4452 1841 358-60-4 (70689), ANZW. There are further letters and more general complaints about the user pays policies, the core services debate and adverse nature of the other changes on children with diabetes throughout several other files in this series: see 358-60-4 (74789), (74885), (70687), and (70688).

In February 1992, National made available targeted subsidies to support people with diabetes based on their medical need or income level, but to questionable effect. If people visited their general practitioner six or more times over six months, and met the previous criteria for the chronically ill certificate, they would be eligible for the High Use Health Card. This provided increased subsidies for subsequent doctor's visits and exemptions from hospital and laboratory part charges (which also came into force in February 1992), but cardholders still had to pay the same rate for prescriptions.²⁰ As most people with diabetes visited their doctor in three monthly intervals to get prescriptions, and the chronically ill criteria remained in place, diabetes societies continued writing oppositional submissions to the government. For those the government believed would not be able to afford health services it introduced a Community Services Card (CSC). The CSC reduced the part-charge on most prescriptions and general practitioner services, and removed all hospital charges for those on certain welfare benefits or meeting a strict income limit.²¹ In cases where the individual could still not afford, or did not understand the new entitlement schemes, or did not see the value in maintaining their doctor's visits and filling their prescriptions, the policy ran counter to the government's goal of a preventive focus for the health system.²²

Hospital part-charges were another problematic policy for diabetes management and the government's stated intentions. The government argued that user charges for hospital services would incentivise people to make better use of primary care services, but undermined this objective by reducing subsidies for general practitioners and pharmaceuticals.²³ By April 1993, in the face of widespread public opposition, non-payment and escalating administrative

²⁰ Katherine O'Regan to Mrs N. Stichman, ABQU 632 W4452 1841 358-60-4 (70689), ANZW.

²¹ For the full details of the schemes and income limits, see Department of Health, *Health Care Charges and Subsidies*, Wellington, 1991.

²² Research from 1996 demonstrated a poor uptake of the CSC for reasons including lack of knowledge about the card and eligibility criteria, the complexity of guidelines and forms and difficulties assessing gross family income: see Toni Ashton, 'The Health Reforms: to Market and Back?', p.146.

²³ Gauld, pp.95-96.

costs, the government backed down on hospital inpatient charges.²⁴ Nevertheless, charges for outpatient diabetes clinics, dietitians and diabetes nurse educators continued until 1997. The system resulted in a variety of charging policies across regions and anomalies such as diabetes education being free in community or domiciliary settings but not at clinics.²⁵

The New Zealand Society for the Study of Diabetes (NZSSD) criticised the disincentive this policy created for preventive care. NZSSD President Professor Jim Mann argued that part-charges ignored the seriousness of diabetes and ‘could lead to an “epidemic” of amputations, kidney disease and eye problems’, which required long hospital stays.²⁶ He saw flawed economic logic in part-charges for outpatient diabetes clinics: ‘For \$31, a patient sees a specialist, a dietitian and a podiatrist. They have their eyes tested and various blood tests taken.... I wonder about the necessity of charging at all, since the \$31 charge is so negligible compared with the overall cost.’²⁷ By contrast, Katherine O’Regan, who was Associate Health Minister and Minister of Consumer Affairs, told people with diabetes that, ‘If people are paying towards the cost of a service then they expect good service.’ She believed this would encourage hospitals to find out what consumers wanted and improve their services.²⁸ This rationale overlooked the problem that, in Mann’s words, ‘There is little point in setting up an excellent system if those who need it most are either not prepared or not able to pay for it.’²⁹ Reflecting on the reforms more recently, Mann recalled that outpatient charges put off a number of his patients attending appointments in Dunedin where he was in charge of diabetes services.³⁰

²⁴ Hamed, pp.14–53.

²⁵ Pat Carlton to Simon Upton, 15 January 1992, Primary Health Care – Diabetes, 1991–92, ABQU 632 W4452 1841 358-60-4, (74789) ANZW.

²⁶ Prof Jim Mann, ‘Health changes ignore the seriousness of diabetes’, *Breakthrough*, Autumn 1992, p.7.

²⁷ *Ibid.*, p.7.

²⁸ Katherine O’Regan, ‘New health system a partnership’, *Breakthrough*, Autumn 1992, p.8.

²⁹ Prof Jim Mann, Memo to all members of the NZSSD, 12 December 1991, Personal Collection of Dr Bob Smith.

³⁰ Prof Jim Mann, Interviewed by C.E. Harper, 2 August 2011.

Contrary to its supposed goal, the targeted, user-pays approach to health services created barriers for preventive diabetes care in low socio-economic groups. New Zealand epidemiological research published in the 1990s suggested an inverse relationship between the risk of developing diabetes and income levels.³¹ Further local surveys estimated up to 60 per cent of people with diabetes were unemployed; many were unable to work because they already had disabling tissue damage or employers were unwilling to take them on due to fears of regular absences.³² Following the 1991 benefit cuts, South Auckland's Whitiara diabetes outpatient clinic reported cases of patients stopping insulin treatment because they could not afford it.³³ Large-scale research conducted in the area between 1992 and 1996 also showed the personal costs of diabetes impeded people's effective management of their condition with up to half of survey respondents reporting that cost affected the regularity of their self-blood glucose monitoring, medication and insulin therapy.³⁴ This may have been a factor in the worsening glycaemic control in respondents over this period.³⁵ The annual out-of-pocket costs for individuals for general practitioners and clinic visits, prescriptions and shoes (people with diabetes are prone to foot problems and require high quality shoes) ranged between \$191 and \$329. As South Auckland was an area where the majority of patients had the CSC, these costs were at the lower end of the scale.³⁶

³¹ Robert Scragg, John Baker, Patricia Metcalf and Evan Dryson, 'Prevalence of diabetes mellitus and impaired glucose tolerance in a New Zealand multiracial workforce', *New Zealand Medical Journal* (NZMJ), 104, 920, 25 September 1991, pp.395–7.

³² David Simmons, Alan Peng, Ara Cecil and Barbara Gatland, 'The personal costs of diabetes in South Auckland: a significant barrier to care in South Auckland', NZMJ, 112, 1097, 8 October 1999, p.285; Dr Colin Tukuitonga, *Improving Health Care for People with Diabetes*, Northern RHA, 1993 p.7; Juliet Ashton, 'Dealing to diabetes – the South Auckland approach', *Health*, 2 April 1992, p.15.

³³ Elizabeth Aitken to David Scott, 24 June 1991, Primary Health Care – Diabetes, 1991, ABQU 632 W4452 1841 358-60-4 (70687), ANZW.

³⁴ Simmons, Peng, Cecil and Gatland, pp.283–5. This research is discussed in more detail in Chapter Seven.

³⁵ David Simmons, Tim Kenealy and David J. Scott, 'Implementing the South Auckland Diabetes Plan: barriers and lessons', NZMJ, 113, 1116, 25 August 2000, p.365.

³⁶ Simmons, Peng, Cecil and Gatland, p.285.

Therefore, while the government claimed its policies would improve access to health services according to need, critics expected they would have the opposite effect for people with diabetes and there is evidence that this was the case. However, diabetes groups stressed prevention of complications as a way the government could reduce the overall costs to the health system; in this regard, they were not adversarial to the government's overarching goal.

DNZ in the 'new health environment'

One of the government's overarching goals with the 'new health environment', devolution of services to the voluntary sector, brought new opportunities for diabetes organisations. DNZ benefitted significantly from a new contractual relationship with government, but this also brought up difficult questions about the appropriate roles for the organisation.

Welfare historian Margaret Tennant has dubbed the relationship between the voluntary and state sectors from the late 1980s as one of 'the contract crunch'.³⁷ So that it could decrease the role of the state in social and health service provision, the government provided contestable state funding for quantifiable 'outputs' agreed to in contracts. For the voluntary sector, such contracts provided opportunities for a more stable income and the expansion of services. Explaining this as both a worldwide trend and a response to these contractual obligations, Tennant argued that 'a strategic shift towards professionalism, training and "capacity-building" was apparent among a range of organisations regardless of size or focus'.³⁸ Such managerial language infiltrated voluntary organisations which were reconceptualised according to commercial criteria as 'non-profits'. The promotion of a corporate model implied a change in the values underpinning voluntary work. Thus Tennant also noted how organisations experienced 'an initial nervousness to a crescendo of complaint' while they

³⁷ Tennant, p.200. The phrase came from a 1995 article in *N.Z. Disabled* about the effect of contracting on voluntary and charitable organisations.

³⁸ Tennant, p.213.

underwent internal changes in order to secure government funding.³⁹ Diabetes organisations were not immune to these developments.

After its false start in the mid-1980s, DNZ entered the 1990s transitioning towards what it called ‘a new era of professionalism’.⁴⁰ DNZ Secretary Murray Jones was running the organisation from his home in Oamaru when in 1988 Lee McLeod, also based in Oamaru, became President, taking on the role as a full-time job.⁴¹ McLeod and Jones began drawing in outsiders with professional skills and the ability to attract corporate sponsorship to the National Executive. The 1989 annual general meeting was a symbolic rebirth of the organisation. The Professional Advisory Panel disbanded with the NZSSD taking over its role in advising on medical issues and health services. The meeting adopted the name change from the New Zealand Diabetes Association to DNZ, a new logo and launched a major national fundraising campaign. Some local diabetes societies disliked the national branding and were unhappy about supplying seeding funds to the campaign; the Public Relations Chairperson, however, temporarily won over discontent explaining that, ‘Societies’ job was to deal with what Rogernomics people call a target market and shortly Society members were going to have to become Professional Managers’ of significant amounts of money.⁴² Although some societies amassed significant money for the fundraising campaign, most struggled and many did not participate at all.⁴³ Moreover, all the money raised went towards expenses, primarily

³⁹ Ibid., p.200. See Chapter Five for a discussion of professionalisation and restructuring efforts in the mid-1980s.

⁴⁰ Annual Report of the New Zealand Diabetes Association for the year ended 31 December 1988, p.15, DNZ. Former Governor-General Sir David Beattie and his wife, whose youngest son had recently been diagnosed with diabetes, became DNZ patrons and Lions Clubs International adopted the campaign as a national project.

⁴¹ Lee Brehaut (nee McLeod), Interviewed by C.E. Harper, 4 July 2011.

⁴² Minutes of the Annual General Meeting of the New Zealand Diabetes Association, 8–9 April 1989, p.6, DNZ.

⁴³ Margaret Jamieson, *The History of Diabetes Nelson Incorporated: Formerly, The Diabetic Association of New Zealand (Nelson Division), 1957–2005*, Nelson, 2005, p.243.

paying the company hired to plan the campaign, which DNZ still owed \$102,000 when it collapsed in 1991.⁴⁴

DNZ's dire financial position drove it to seek government funding and into 'the contract crunch'. In early 1991 McLeod and Jones met with O'Regan to request financial support for DNZ's National Office. A Health Department contracts manager did not look favourably on the request, as 'it is very difficult in these cases to establish what measurable outputs we are being asked to purchase'.⁴⁵ O'Regan initially advised DNZ that she could not help.⁴⁶ Within a few months, DNZ was so indebted it was no longer permitted to operate a bank account and faced immediate dissolution. O'Regan asked the Minister of Health, Simon Upton, if they could reconsider because the organisation was useful, cheap and its educational work supported the government's desire to reduce inpatient services.⁴⁷ Upton agreed and authorised a contract requiring DNZ 'to develop effective marketing strategies with the object of self-sufficiency'.⁴⁸ DNZ signed a further contract in February 1992 for government-dictated 'outputs' to increase subscriptions to its national magazine, work on a public awareness project and take positive steps towards organisational development.⁴⁹ The latter included having external consultants Ernst & Young prepare DNZ's first strategic plan so DNZ could 'position itself to take full advantage of future sources of funding made available by health system reforms'.⁵⁰ As O'Regan told DNZ's annual conference, it needed to meet 'the

⁴⁴ Three members of DNZ's National Executive managed to negotiate down Kavanagh's fees and the NZSSD wrote off its seeding loan as a donation enabling DNZ to remain solvent: *ibid.*, p.244.

⁴⁵ Chris Shelton, Acting Manager Independent Service Provider Contracts to Russell Ritchie, Manager Health Services, 4 June 1991, ABQU 632 W4452 1841 358-60-4 (70687), ANZW.

⁴⁶ O'Regan to Lee McLeod, 1 July 1991, ABQU 632 W4452 1841 358-60-4 (70687), ANZW.

⁴⁷ O'Regan to Upton, 4 September 1991, ABQU 632 W4452 1841 358-60-4 (70687), ANZW.

⁴⁸ Steve Anderson, General Manager, Contract Management Group, to Upton, 30 September 1991, ABQU 632 W4452 1841 358-60-4 (70687), ANZW.

⁴⁹ Agreement for supply of goods and services between the Minister of Health and DNZ, 20 February 1992, ABQU 632 W4452 1841 358-60-4 (74789), ANZW.

⁵⁰ Ernst & Young, *DNZ Strategic Plan, 1992-94*, ABQU 632 W4452 1841 358-60-4 (74789), ANZW.

challenge’ of how it would ‘fit into the health environment, to identify the nature and costs of services you might be able to provide’ in order to get contracts with the new RHAs.⁵¹

DNZ was on its way to meeting this challenge with a supply scheme for diabetes-related products. Murray Jones had started a mail order service for non-medical products, like artificial sweeteners, in the late 1980s. Not long after, Jones established contact with the Health Department’s Brian Hepenstall. Hepenstall was responsible for managing (and trying to reduce) the government’s pharmaceutical schedule and was studying Diabetes Australia’s scheme of distributing government-subsidised equipment to people with diabetes.⁵² He worked out a proposal for a similar scheme using DNZ to distribute blood glucose testing strips and took it to the then Labour Minister of Health Helen Clark to, in his words, ‘see if the concept was politically acceptable’.⁵³ Clark endorsed the proposal but it did not get much further because of the change of government in November 1990.

National’s agenda with the new health system offered an opportunity for Jones to revive the test strip proposal. He approached O’Regan to lobby her about the high costs people with diabetes faced for health services. Despite her government’s user-pays philosophy, O’Regan claimed these costs were unacceptable and she agreed to the merits of DNZ selling discounted blood glucose testing strips.⁵⁴ O’Regan guided DNZ through protracted negotiations with

⁵¹ O’Regan ‘A challenge’, p.11.

⁵² Jones was in Wellington meeting with his former doctor, Dr John Crawford, who had taken up a position in the Department; Crawford introduced Jones to Hepenstall as he knew he was looking into diabetes pharmaceutical supplies: Brian Hepenstall, Interviewed by C.E. Harper, 9 July 2011; Murray Jones, Interviewed by C.E. Harper, 9 November 2012. Hepenstall explained the Australian model was quite different, having a research motivation (collecting statistical data on people with diabetes), not just a cost-saving motivation and Diabetes Australia was much more closely aligned with the Federal government than DNZ was at this time. For more on the scheme, see F.I.R. Martin, *A History of Diabetes in Australia*, Melbourne, 1998, pp.83–86.

⁵³ Brian Hepenstall, Interviewed by C.E. Harper, 9 July 2011.

⁵⁴ Murray Jones, Interviewed by C.E. Harper, 9 November 2012; Bee Dawson, *Dedicated to Diabetes: Diabetes New Zealand 1962–2002*, Wellington, 2002, p.66.

RHAs and the contract was finally signed off on Christmas Eve 1993.⁵⁵ It allowed anyone with diabetes (not just diabetes society members) to mail their prescriptions to DNZ, which would send back the strips; the only cost to the consumer was \$1.50 for postage. The supply scheme saved the government money too through the elimination of pharmacy costs.

The supply scheme meant a significant new role for DNZ that invited controversy. To use one of Tennant's phrases, 'internal angst seeps through the records'.⁵⁶ Jones had difficulty convincing DNZ's Executive of the scheme's benefits; it agreed to a one-year trial only after he informed it O'Regan had threatened to put the contract out to tender.⁵⁷ The NZSSD also had concerns about DNZ becoming a service provider without clinician oversight of the medical products available and communications with the medical profession.⁵⁸ Meanwhile, local societies complained of a lack of consultation. Many did not believe Jones was unable to talk to them earlier due to the commercial sensitivities around the contract negotiation. Others fretted about what government contracts meant for the independence and ability of the organisation to lobby and advocate for people with diabetes.⁵⁹ At the 1993 annual meeting there was even a motion put forward (and lost) that the supply scheme was unconstitutional.⁶⁰

This opposition reflected larger tensions within voluntary organisations which were feeling coerced into the corporate ideologies of the 1990s. Tennant has pointed out the difficulties of changing operations when most non-profit organisations in New Zealand were still local,

⁵⁵ DNZ Annual Report 1993, p.18, DNZ. The final contract was with the Pharmaceutical Management Agency (PHARMAC), which the four RHAs created in mid-1993 to purchase pharmaceuticals on their behalf. Health Department Officials and DNZ representatives have recorded their perception that O'Regan had a genuine interest in working constructively with them on diabetes issues: see Fran McGrath to Ian Johns, 15 March 1991, Primary Health Care – Diabetes, 1990–91, ABQU 632 W4452 1841 358-60-4 (69554), ANZW; Murray Jones, Interviewed by C.E. Harper, 9 November 2012.

⁵⁶ Tennant, p.206.

⁵⁷ Dawson, p.66.

⁵⁸ *Newsweet: Newsletter of the NZSSD*, 2, October 1992, p.2.

⁵⁹ Minutes of the Annual General Meeting of DNZ, 12 April 1992, pp.12–14, DNZ.

⁶⁰ Minutes of the Annual General Meeting of DNZ, 18 April 1993, p.18, DNZ.

community-based, 'administratively unsophisticated' and run by traditional volunteers.⁶¹ Certainly, no matter how glossy DNZ's annual reports became or how many 'outputs' it achieved, in the words of John Denton, DNZ's President from 1996–98, it still struggled to convince its 'family of societies' of the need 'for greater professionalism and a more business-like approach'. Denton argued they needed to accept they could no longer depend solely on volunteers and take responsibility for building 'capacity'.⁶²

Jones' perseverance with the supply scheme paid dividends for DNZ and helped resolve some of the reticence to change. Jones and his wife June continued to develop the supply scheme which generated DNZ a growing income; Jones recalled that by the end of the decade it was making half a million dollars annually.⁶³ It worked because it gave DNZ a competitive advantage over pharmacies with National's \$15 prescription charges. The scheme allowed the expansion of the national organisation, attracted new members and helped fund education and awareness activities. A separate board ran the supply scheme to protect it from internal politics.⁶⁴ On reflection, Jones believed the supply scheme gradually helped improve relations with local societies as they could see that DNZ was actually 'doing something'.⁶⁵

Thus, DNZ's supply scheme demonstrated some of the potential of the new health environment for voluntary organisations. However, considering the negative impact of the government's social policies on many people with diabetes, it is likely the government viewed the scheme as a cost-saving measure and was not simply a triumph of consumer advocacy; the opposition it generated within DNZ confirms this. Nevertheless, DNZ became a government-

⁶¹ Tennant, p.214.

⁶² DNZ Annual Report 1996, p.5, DNZ; John Denton, Interviewed by C.E. Harper, 6 July 2011.

⁶³ Dawson, p.68.

⁶⁴ Murray Jones, Interviewed by C.E. Harper, 9 November 2012; Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

⁶⁵ Murray Jones, Interviewed by C.E. Harper, 9 November 2012.

endorsed service provider and raised the profile of diabetes with government through its interactions with O'Regan.

'Our people are reluctant to use the public health system'

In 1993, DNZ presented the government with a report on Maori and Pacific peoples' attitudes towards diabetes services. This conveyed some clear messages: 'Our people are reluctant to use the public health system because the values, practices and procedures are foreign to us... There is a misunderstanding between the palagi [Pakeha/western] health professionals and Samoan people on the concept of health'. 'Samoan nurses will be the role model to solve this issue that affects most Samoans' and 'we as Maori ... are of the view that, Maori will be responsible for Maori'.⁶⁶ In the 'new health environment', the larger burden of diabetes in Maori and Pacific communities appeared to demonstrate the failings of the state's delivery of health services. As the above statements suggest, Maori and Pacific people wanted to find their own solutions.⁶⁷

By the 1990s there was growing epidemiological evidence that Maori and Pacific people suffered disproportionately from diabetes. Studies had long established the significantly higher prevalence of non-insulin-dependent diabetes (NIDDM) and mortality rates among Maori and Pacific people compared to Pakeha; in the 1980s and 1990s research effort went into surveying patterns of care, metabolic and clinical characteristics and complications. This research found Maori and Pacific people developed diabetes ten years earlier than Pakeha, were more overweight and had poorer glucose control.⁶⁸ Maori had an earlier onset of

⁶⁶ DNZ, *Report to the New Zealand Government: Maori and Pacific Island Service Liaison Report*, 1993, unpaginated.

⁶⁷ See Chapter Seven for more in-depth discussion of Maori and Pacific diabetes initiatives in South Auckland.

⁶⁸ H. Lunt, C.W. Lim, M.J. Crooke and R. B. Smith, 'Clinical and ethnic characteristics associated with urinary albumin excretion in non-insulin-dependent diabetic subjects attending the Wellington Hospital diabetes clinic',

complications and an excess of diabetic nephropathy (kidney damage).⁶⁹ South Auckland evidence showed Maori and Pacific hospital patients with diabetes had a renal failure rate of 20 per cent compared to 0.5 per cent for Pakeha.⁷⁰ Another South Auckland study revealed 8 per cent of Pacific people with diabetes had lost sight in at least one eye compared to 2 per cent of Pakeha in the study population.⁷¹

These outcomes often paralleled differences in Maori and Pacific experiences of diabetes care. According to South Auckland surveys, Pacific people with diabetes were less likely than Pakeha to receive education at first diagnosis and only 1 per cent had what the researchers deemed an adequate knowledge of diabetes.⁷² Dr David Simmons, project leader of these South Auckland studies, estimated that only around 20–25 per cent of Maori and Pacific people diagnosed with diabetes were actually getting treatment: ‘They come into our emergency department requiring amputation, long-stay treatment for infections, or for heart attacks. Or they walk in with renal failure’.⁷³ A major problem was the lower socio-economic status of Maori and Pacific patients; in South Auckland 37 per cent of Pakeha, 62 per cent of Maori and 75 per cent of Pacific men of working age with diabetes were unemployed.⁷⁴ For the country in general, Pacific health agencies identified additional problems for mainstream education of Pacific people with diabetes due to language, cultural differences and shyness or

NZMJ, 103, 887, 11 April 1990, pp.143–5; David Simmons ‘The epidemiology of diabetes and its complications in New Zealand’, *Diabetic Medicine*, 13, 4, 1996, pp.372–3.

⁶⁹ D. Simmons, L. M. Shaw, D.J. Scott, T. Kenealy and R.K. Scragg, ‘Diabetic nephropathy and microalbuminuria in the community’, *Diabetes Care*, 17, 12, December 1994, pp.1404–10.

⁷⁰ Simmons ‘The epidemiology of diabetes’, p.373.

⁷¹ *Ibid.*, p.374.

⁷² South Auckland Community Diabetes Planning Group, *Sugar Busters: Diabetes in South Auckland*, November 1992, p.5; David Simmons, Lois Shaw, Tim Kenealy, David Scott and Robert Scragg, ‘Ethnic differences in diabetes knowledge and education: the South Auckland Diabetes Survey’, NZMJ, 107, 978, 25 May 1994, pp.197–200.

⁷³ Juliet Ashton, ‘Dealing to diabetes’, p.15.

⁷⁴ Simmons ‘The epidemiology of diabetes’, p.372.

embarrassment.⁷⁵ Maori health providers emphasised the tendency for existing health services to ‘compartmentalise the Maori person’, a lack of culturally appropriate resources and ‘a mystification of health within the community’ leaving Maori ‘powerless to take responsibility for their own well-being’.⁷⁶

The health reforms offered opportunities to expand the ‘by Maori for Maori’ approach to health services. Maori health was a key political issue in the 1980s, explicitly linked to goals of self-determination and upholding the principles of the Treaty of Waitangi. Signed in 1840 by fifty Maori chiefs and a representative of the British Crown, the Treaty of Waitangi ceded sovereignty to the British Crown in exchange for Maori to have the rights and privileges of British subjects. It also guaranteed protection of Maori property and, in the Maori version, taonga (treasures), which came to be interpreted as including the protection of health.⁷⁷ Maori activism highlighted how the welfare state had failed to meet the needs of Maori and spurred more Maori participation in health care provision and health promotion based on Maori values and at settings such as marae (meeting places).⁷⁸ The fourth Labour government and National in the 1990s incorporated a bicultural rhetoric into health policy. At a tangible level, they began contracting services to iwi (tribes) and other Maori providers. The government directed RHAs to aim towards bringing Maori health status up to that of non-Maori, and many Maori groups were hopeful that the government’s contracting agenda would open up spaces for

⁷⁵ For example, see ‘Matua Pasefika Welfare Trust, Christchurch’, in DNZ, *Maori and Pacific Island Service Liaison Report*, (appendix 1.1A).

⁷⁶ ‘Report from Te hau Ora O Te Tai Tokerau’, in DNZ, *Maori and Pacific Island Service Liaison Report*, (appendix 1.1A). This is not to imply all Maori were unhappy with mainstream services; Maori in Christchurch utilised the specialist complications screening clinic equitably and reported being happy with the Canterbury region’s services. Nevertheless, 20 per cent still suggested they would prefer a marae-based clinic given the choice and diabetes services had already employed a lay diabetes Maori health worker: see Danny de Lore, Ariki Hamilton, Laurie Brown and Helen Lunt, ‘Maori attitudes to diabetes and diabetes health care delivery in North Canterbury’, *NZMJ*, 106, 950, 24 February 1993, pp.60–61.

⁷⁷ Linda Bryder, ‘Health citizenship and “Closing the Gaps”: Maori and health policy’, Astri Andersen, ed., *Citizens, Courtrooms, Crossings: Conference Proceedings*, Bergen, 2008, p.53.

⁷⁸ L.A. Ferguson, ‘Marae Based Health Initiatives within the Tainui Iwi from 1970–1995’, MA thesis, University of Auckland, 1997; Mason Durie, *Whaiora: Maori Health Development*, Auckland, 1994.

further Maori health development and autonomy.⁷⁹ A trend towards ‘by Pacific for Pacific’, which built on the Maori experience, also emerged in the primary care sector in the early 1990s.⁸⁰ Government contracts also drew DNZ into greater consideration of Maori and Pacific needs.

One of the ‘outputs’ government purchased from DNZ in 1993 was a Maori and Pacific liaison project to find out what these communities wanted in diabetes services. DNZ deployed a sub-committee to organise the consultation, which ended in a report of recommendations and presentation to the Minister of Health in September 1993. Both the Maori and Pacific consultations highlighted the need for more affordable services. The majority of other recommendations emphasised culturally specific needs and self-determination. The Pacific report noted the need for Pacific language education materials, bilingual education workers, more qualified Pacific health professionals, cultural awareness seminars for non-Pacific health professionals and Pacific people working in partnerships with researchers to develop new diabetes interventions; all these actions needed to ‘be monitored regionally and nationally by Pacific Island’s people’.⁸¹ This sentiment came across even stronger in the Maori consultation where a major focus was on the ‘token’ biculturalism of government-provided health services.⁸² A workshop in Taranaki revealed that ‘all felt that a service of education done by Maori for Maori with Pakeha being slotted in for added input was a way to deal with Maori’.⁸³ The national recommendations included appointing a Maori co-ordinator (or possibly several) to manage the reorganisation of existing services, establishing more

⁷⁹ Durie, p.176; Tennant, p.196.

⁸⁰ Deborah Dunsford, Julie Park, Judith Littleton, Ward Friessen, Phyllis Herda, Pat Neuwelt, Jennifer Hand, Philippa Blackmore, Sagaa Malua, Jessica Grant, Robin Kearns, Linda Bryder and Yvonne Underhill-Sem, *Better Lives: the Struggle for Health of Transnational Pacific Peoples in New Zealand*, Auckland, 2011, p.57.

⁸¹ ‘Pacific Islands Report’, August 1993, in DNZ, *Maori and Pacific Island Service Liaison Report*, section one.

⁸² ‘Comments from Auckland Healthcare Community Services, Auckland Diabetes Centre’, in DNZ, *Maori and Pacific Island Service Liaison Report*, appendix 2.4.

⁸³ ‘Report from He Matehuka Diabetes Project 1993 Taranaki’, in DNZ, *Maori and Pacific Island Service Liaison Report*, appendix 2.7.

community and marae-based clinics, funding more Maori educators and health promotion campaigns through iwi networks.⁸⁴

DNZ's contracted liaison also resulted in a new diabetes organisation by, and for, Maori with diabetes and their families. Some Maori groups whom DNZ had consulted felt that DNZ was not meeting the needs of Maori people with diabetes. At a national diabetes hui (meeting) in 1993 a number of Maori spoke forcefully that they should form their own organisation which was not affiliated to DNZ.⁸⁵ Over the next year, 400 individuals registered interest in Te Roopu Mate Huka o Aotearoa – the National Maori Diabetes Organisation. Te Roopu Mate Huka planned to establish national, regional and district groups to advocate for Maori with diabetes, develop awareness and promote self-care among Maori. This also involved lobbying CHEs to ensure Maori participation in planning and delivery of diabetes services and to establish one full-time Maori diabetes community educator per 10,000 people with diabetes.⁸⁶

In a letter informing medical professionals of the formation of Te Roopu Mate Huka, the founders explained that 'there is no intention to further fragment the representation for diabetes, but rather to promote the involvement of Maori patients and their whanau [family] in their own diabetes care'.⁸⁷ They downplayed divisions with DNZ to present a united image for diabetes advocacy. DNZ responded to the liaison findings with having a Te Roopu Mate Huka and a Pacific representative sit on its Council.⁸⁸ In 1994, diabetes consumer groups including Te Roopu Mate Huka, the NZSSD, and an organisation called Pacific Island Health

⁸⁴ 'Maori Report', September 1993, in DNZ, *Maori and Pacific Island Service Liaison Report*, section two.

⁸⁵ 'Minutes of the Diabetes Output Hui held at Diabetes Auckland, Friday 3 September 1993', in DNZ, *Maori and Pacific Island Service Liaison Report*, appendix 2.6; Prof David Simmons, Interviewed by C.E. Harper, 5 April 2012.

⁸⁶ Dr D.K. McLeod, *Diabetes: A Review of Diabetes in the Central Region*, Wellington, 1994, p.84.

⁸⁷ 'National Maori Diabetes Organisation', NZMJ, 107, 978, 25 May 1994, p.208.

⁸⁸ Minutes of the Annual General Meeting of DNZ, 17 April 1994, p.13, DNZ.

and Welfare, formed the National Diabetes Forum to facilitate joint interests in interacting with government.

‘Real diabetes’

Beneath a united façade of diabetes advocacy were simmering tensions. As former DNZ President (1987–88, 2002–04) Russell Finnerty has reflected, what he affectionately called the ‘vicious paediatric mums’ lobby’ felt that perceptions of people with diabetes as fat and lazy were sullyng the image of ‘real diabetes’.⁸⁹ Real diabetes, in their minds, was the autoimmune condition IDDM (Type 1), which usually developed in childhood and meant a life-long reliance on medical technologies for survival. In a climate of dwindling state resources for health and welfare, increasing attention on those ‘at risk’ of the more common NIDDM (Type 2), worried those with Type 1 and their families.⁹⁰

The formation of Diabetes Youth in 1991 reflected young people with diabetes and their families’ concerns that they did not have sufficient public and political visibility in an uncertain welfare environment. An informal steering group of people interested in youth issues held discussions at DNZ’s 1990 annual meeting after a dispute between local societies over the yearly national children’s camp and a lack of national guidelines.⁹¹ This meeting decided to establish Diabetes Youth, a co-ordinating national body for local branches parallel to DNZ, which became operational the following year. Its key concerns were raising community awareness and providing tangible recreational activities, support and education services. According to its President, these services were free to members because of ‘the

⁸⁹ Russell Finnerty, Interviewed by C.E. Harper, 18 July 2011.

⁹⁰ Since 1979, diabetes had been classified into Type I and Type II but was most commonly referred to as IDDM and NIDDM. Over the 1990s, there was a gradual shift towards using Type 1 and 2 to avoid the confusion around insulin-treated NIDDM.

⁹¹ Dawson, p.58; DNZ Annual Report 1990, pp.44–45, DNZ.

financial hardships increasingly being experienced by families'.⁹² Diabetes Youth had a clear advocacy agenda to lobby against health changes it claimed were discriminatory and impeded the rights of young people with diabetes to live a 'normal' life.

That Diabetes Youth believed DNZ could not fulfil this agenda alone hints at tensions over DNZ's new relationship with government and its focus shifting to Type 2.⁹³ Former Medical Panel member Dr Bob Smith has recalled that when he first began attending local diabetes society meetings in the 1970s, they 'seemed to always be dominated by mothers of children with diabetes and their needs and perceptions', but over time Type 2 problems became more dominant.⁹⁴ As discussed in the previous chapter, in 1990 DNZ lobbied the Minister of Health Helen Clark for 'further targeting' of resources to adult-onset diabetes and Clark required area health boards to report on interventions for 'high-risk' groups. This focus increased as DNZ contracts with government targeted Type 2 diabetes in public health education campaigns. A joint Health Department, Lions and DNZ National Diabetes Awareness Project over 1991 and 1992 included seminars for primary care providers, television and radio advertising, a press kit, special promotions in shopping malls and travelling detection caravans to screen at-risk groups.⁹⁵ The Project also produced a video for those newly diagnosed with Type 2. Entitled *Who's in Control?*, the video imparted the message people with Type 2 had to take control of their diet and exercise rather than letting diabetes control them.⁹⁶ While young IDDMs were

⁹² DNZ Annual Report 1991, pp.22–23, DNZ.

⁹³ In the United States, one of the reasons behind the establishment of the Juvenile Diabetes Foundation in 1970 was parents' concerns that the American Diabetes Association was more focused on adult-onset diabetes and did not devote enough fundraising and research effort to finding a cure for juvenile-onset diabetes: see Aaron Mauck, 'Managing Care: The History of Diabetes Management in Twentieth Century America', PhD dissertation, Harvard University, 2010, pp.314–15.

⁹⁴ Dr Bob Smith, Personal Communication, 3 June 2011.

⁹⁵ Health Education – Diabetes, 1991–92, ABQU 632 W4452 1590/ 344-23-18-1 (73001), ANZW; Health Education – Diabetes, 1991–92, ABQU 632 W4452 1590/ 344-23-18-1 (76555), ANZW.

⁹⁶ Department of Health, *Who's in Control?*, 1992, Television New Zealand Archives, Wellington (TVNZ).

encouraged ‘towards self-sufficiency’ in managing their diabetes, they could hardly be held responsible for developing an autoimmune condition.⁹⁷

A new stigma emerged with media focus on diabetes as a lifestyle disease. In what became a stereotypical presentation, *Consumer* magazine published an article in 2000 entitled ‘Diabetes, Disease of the Couch Potato’, which sparked outrage amongst parents of children with diabetes. Diabetes Youth Wellington wrote an open letter to the Consumers’ Institute that such ‘ignorant accusations’ created ‘a stigma that children with diabetes can do without’, as could a number of professional New Zealand athletes with Type 1 diabetes.⁹⁸ Older people with Type 1 also resented the obesity association in the media.⁹⁹ The implication that people who developed diabetes were makers of their own destiny through poor lifestyle choices, an insult enough for people with Type 2, was unacceptable to people with Type 1 who clearly had no ‘choice’ in their destiny. The new stigma of the couch potato compounded the older ones of being different, or an employment risk, and threatened to overturn decades of publicity efforts demonstrating people with diabetes could, and did, lead ‘normal’ active lives.

Over the 1990s, the increased government, DNZ and media focus on the person with diabetes as fat and Maori or Pacific seemed to overshadow the special needs of young people with diabetes. The formation of Diabetes Youth aimed to meet these needs and lobby government to do the same.

⁹⁷ On the development of the self-sufficiency philosophy, see Chapter Four.

⁹⁸ The writer was careful to point out that a significant proportion of those with Type 2 diabetes were also not obese or inactive: see Crystal Bridger, Diabetes Youth Wellington, ‘An open letter re: “Diabetes, Disease of the Couch Potato”’, 10 November 2000, URL: <http://www.scoop.co.nz/stories/GE0011/S00041/re-diabetes-disease-of-the-couch-potato.htm>, accessed 5 June 2013. Dr Bob Smith, who was a diabetes specialist in Wellington, has recalled first-hand experience with parents ‘indignation’ over this story: Personal Communication, 3 June 2011.

⁹⁹ B.J.W. Houlahan, ‘Obesity and diabetes’, *Evening Post*, 9 September 1999.

A ‘National Plan of Action on Diabetes’

In 1994 Associate Minister of Health, Katherine O’Regan, announced that a working party of consumers, experts and health officials would formulate a ‘National Plan of Action on Diabetes’ (NPAD). This plan would cut ‘across traditional boundaries between health professionals and patients, and between hospitals and communities’.¹⁰⁰ Instead of boundaries, NPAD would set out an integrated approach to the prevention and control of diabetes. O’Regan claimed that it was ‘fortunate that this change of emphasis in tackling diabetes is occurring at a time a fundamental shift is taking place in how we manage health care delivery’.¹⁰¹

Under the area health board system there had been policy guidance for local diabetes services. As noted in the last chapter, the Health Department’s 1988 service planning guidelines, the *Diabetes Mellitus: A Model for Health Maintenance*, stressed ‘shared care’ between general practitioners, diabetes resource teams and the person with diabetes, as well as integrated non-communicable disease lifestyle interventions for high-risk populations – the kind of boundary-crossing approach O’Regan described six years later.¹⁰² Few boards, however, had implemented diabetes plans along these lines due to financial constraints and difficulties defining measurable outcomes to link to their performance contracts.¹⁰³ By 1991, the Department stated it had moved away from what it called the ‘prescriptive’ style of the guidelines’ recommendations for staffing levels and resource allocation, towards a focus on

¹⁰⁰ O’Regan ‘A challenge’, p.11.

¹⁰¹ Murray Jones, ‘Presentation of the New Zealand Declaration on Diabetes: report by the Executive Director’, *Breakthrough*, 6, 4, Summer 1994–95, p.14.

¹⁰² D.W. Beaven and Dorothy Neal, eds, *Diabetes Mellitus: A Model for Health Maintenance: Service Planning Guidelines for Area Health Boards*, Wellington, 1988, p.33.

¹⁰³ Dr Ian McPherson to Dr Andrew Holmes, 7 December 1990, ABQU 632 W4452 1841 358-60-4 (69554), ANZW; Jeanette Crossley, ‘Funds to implement diabetes plans are hard to identify’, *New Zealand Doctor*, 2 April 1990, p.11.

the desired results.¹⁰⁴ The Health Department were working on further policy guidance; it commissioned the Christchurch Diabetes and Lipids Research Group to do a literature review with recommendations for Boards on the early diagnosis of and intervention for NIDDM.¹⁰⁵ As the National government's reform plans progressed, the purpose of the literature review was reinterpreted as being 'to develop policy advice on diabetes issues aimed at reducing mortality and morbidity' to help define the core services deserving public funding.¹⁰⁶

Once the health reforms were in place, the Public Health Commission (PHC) took responsibility for policies to address diabetes mortality and morbidity. In March 1994, the PHC released its public health strategy document, *A Strategic Direction to Improve and Protect the Public Health*. This policy advice to the Minister of Health set priorities derived from a previous PHC report on the state of public health, lengthy public consultation and advice from Dr Terry Sullivan, a WHO consultant who had been responsible for developing a public health strategy for Ontario, Canada.¹⁰⁷ It recommended six broad-based public health goals, four of which centred on stages in the life course. Under the fifth goal 'to improve and protect the health of adults', one of the five objectives was to reduce disability and death rates from diabetes, with target development to begin in 1995/96.¹⁰⁸

Internationally, diabetes had become the subject of major public health policy recommendations by the 1990s. The World Health Assembly passed its 42nd Resolution in

¹⁰⁴ Ian Miller, Acting Director-General of Health to Professor D.W. Beaven, 17 April 1991, ABQU 632 W4452 1841 358-60-4 (69554), ANZW.

¹⁰⁵ HSRDU – Diabetes Literature Review, 1991–92, ABQU 632 W4452 1957 372-22/25 (73299), ANZW.

¹⁰⁶ Policy Specification to Minister of Health, 19 March 1992, ABQU 632 W4452 1957 372-22/25 (73299), ANZW; L.J. Brown and R.S. Scott, *Early Detection, Diagnosis and Intervention for Adult-Onset Diabetes Mellitus in New Zealand: A Review of Literature Relevant to the Development of Policies for Diabetes Services*, Wellington, 1992.

¹⁰⁷ For more on the PHC's methodology, see PHC, *A Strategic Direction to Improve and Protect the Public Health*, March 1994, Wellington, pp.12–14; Louise Signal and Gillian Durham, 'A case study of health goals in New Zealand', *Australian and New Zealand Journal of Public Health*, 24, 2, April 2000, pp.192–7.

¹⁰⁸ PHC, *A Strategic Direction*, p.31.

1989, which required member states to assess the national importance of diabetes, develop population-based measures to prevent and control it, expand training and education, and integrate services at the community level.¹⁰⁹ The United States had begun this process in the 1970s, but with a greater focus on research, and released an updated Long-Range Plan to Combat Diabetes in 1987. In 1989 a joint meeting of the WHO and International Diabetes Federation (IDF) in Italy endorsed a set of standards for diabetes care with five-year targets for reducing morbidity from complications and measuring the effectiveness of care at the population level, known as the *St Vincent Declaration*.¹¹⁰ The WHO released guidelines in 1991 to help member states institute the 42nd resolution. These suggested the formation of working parties representing health authorities, professionals and interest groups to plan national programmes. The Australian Diabetes Society (a professional organisation) released a *National Plan of Action on Diabetes* in 1993. The following year the WHO issued a technical report with recommendations on the primary prevention of diabetes.¹¹¹

Consumer and health professional groups utilised these international recommendations to push for action in New Zealand. O'Regan met a deputation of representatives from the various diabetes groups in 1993 who, she later stated, convinced her to adopt the WHO Resolution on Diabetes.¹¹² The following year consumer and professional groups presented O'Regan with the *New Zealand Declaration on Diabetes Mellitus*, which adopted the *St*

¹⁰⁹ 'Notes of a steering group meeting for a diabetes action plan held at the PHC on 23 February 1995', in NPAD Working Party Agenda Papers, 15 November 1995, Personal Collection of A/Prof Tim Kenealy.

¹¹⁰ The targets were to: reduce new blindness due to diabetes by one third or more; reduce numbers of people entering end-stage diabetic renal failure by at least one third; reduce by one half the rate of limb amputations for diabetic gangrene, cut morbidity and mortality from coronary heart disease in the diabetic by vigorous programmes of risk factor reduction; achieve pregnancy outcome in the diabetic woman that approximates that of the non-diabetic woman: see 'Diabetes care and research in Europe: the Saint Vincent Declaration', *Diabetic Medicine*, 7, 4, 1990, p.360.

¹¹¹ All these documents were provided for the first official NPAD meeting: NPAD Working Party Agenda Papers, 15 November 1995, Personal Collection of A/Prof Tim Kenealy

¹¹² Jones, 'Presentation of the New Zealand Declaration', p.14.

Vincent Declaration targets.¹¹³ At the presentation ceremony, O'Regan reported that she had requested the Ministry of Health to convene a meeting with the Core Services Committee, PHC and other interested groups to discuss joint initiatives on diabetes and that they would be assembling a working party of experts and people with diabetes to begin constructing an action plan.¹¹⁴ This was in line with the WHO's 1991 guidelines. In February 1995, a 'diabetes steering group' met at the PHC where they learned that the PHC's *National Action Plan on Nutrition*, a ten year strategy also evolving from WHO directives, gave top priority out of its new target initiatives to the development of the same for diabetes.¹¹⁵ A NPAD Working Party, which included representatives from DNZ, the NZSSD, the Royal New Zealand College of General Practitioners (RNZGP), Te Roopu Mate Huka o Aotearoa, Pacific communities, diabetes nurse specialists, community educators, a prominent epidemiologist and a nutritionist was established. A Core Services diabetes group, set up to produce management guidelines for primary care, would also act as an advisory body to the Working Party, facilitated by the dual membership of Dr Rick Cutfield (a diabetes specialist) and Dr Tim Kenealy (a general practitioner).¹¹⁶ The Working Party felt considerable optimism that the government was committed to national action on diabetes.

In light of the international impetus towards diabetes action plans and ongoing policy work since the 1980s, O'Regan overstated the significance of the health reforms in determining a new approach to diabetes prevention and control. Nevertheless, the reforms did provide a

¹¹³ *New Zealand Declaration on Diabetes Mellitus*, Presented to the Government of New Zealand by the People of New Zealand, Wednesday November 16th 1994, Personal Collection of Dr Rick Cutfield; Jones, 'Presentation of the New Zealand Declaration', p.14. The government, however, did not commit to implementing the Declaration.

¹¹⁴ *Ibid.*, p.14.

¹¹⁵ 'Notes of a steering group meeting for a diabetes action plan held at the PHC on 23 February 1995'

¹¹⁶ Minutes of a steering group teleconference on development and implementation of diabetes practice guidelines, 12 October 1994, Personal Collection of A/Prof Tim Kenealy.

space for diabetes to get on the national policy agenda through the work of the PHC and the O'Regan's involvement with diabetes consumer groups.

'Will government act on diabetes?'

No sooner had diabetes become a public health policy priority when national action appeared in jeopardy. In December 1994, the Minister of Health Jenny Shipley announced that she would dissolve the PHC. Ostensibly, this was because of the complexity and overlaps in its advisory function with the Ministry. However, it may have had more to do with the PHC's critical stance on government welfare policy and pressure from food, tobacco and alcohol industries opposed to its recommendations.¹¹⁷ A new National-New Zealand First coalition government introduced further changes to the health system and its spending priorities in late 1996. Under the headline 'Will government act on diabetes?' a May 1997 article in the *New Zealand Doctor* reported the concerns of prominent Auckland diabetes physicians that the 'long-awaited national action plan has been downgraded to a strategy document prior to its imminent release'.¹¹⁸ Whereas an action plan outlined specific objectives, resources and mechanisms for review, a strategy provided merely a framework of recommendations.

The dissolution of the PHC changed the responsibilities for, and nature of the NPAD. The PHC effectively closed in mid-1995 with its advisory function transferred to the Ministry of Health's new Public Health Group and purchasing function transferred to RHAs. The Public Health Group would produce the NPAD, while the Working Party was renamed the 'Diabetes Advisory Group' and was only to advise the Ministry on research and approach. The plan would form 'flexible' advice for RHAs, which had, to various extents, been assessing diabetes

¹¹⁷ Gauld, pp.122–5; Marten Hutt and Philippa Howden-Chapman, 'The Making of Alcohol Policy', in Peter Davis and Toni Ashton, eds, *Health and Public Policy in New Zealand*, Melbourne, 2001, pp.255–72. Marten Hutt and Philippa Howden-Chapman, *Old Wine in New Bottles: The Public Health Commission and the Making of New Zealand Alcohol Policy*, Wellington, 1998.

¹¹⁸ Hugh Patterson, 'Will government act on diabetes?', *New Zealand Doctor*, 28 May 1997, p.68.

needs and planning purchasing strategies.¹¹⁹ There would be no mechanism to ensure RHAs would achieve a balance of public health programmes and personal health services for diabetes. In September 1996, the Ministry released a consultation draft prefaced with the statement that although RHAs should act on its recommendations, this was to be ‘within the confines of current resources’ and have the aim of creating ‘efficiency gains within the health sector’.¹²⁰ Those making submissions did not miss these points and expressed doubt that the plan would achieve anything without more funding and a dedicated national team to monitor its implementation.¹²¹

Following the October 1996 election, the National party went into coalition with New Zealand First, a populist party that had expressed intentions to replace the competitive focus of the health system with a collaborative and better funded one. New Zealand First had made health a key election issue, tapping into the widespread public opposition to user pays, cost-cutting and administrative failures of the reforms. The Coalition Agreement on Health determined that the four RHAs would merge into one funding agency and CHE’s would no longer be profit-driven.¹²² It intimated a shift away from awarding contracts to the lowest bidder towards long-term contracts based on benchmarking. There would be increased government funding with priority given to reducing elective surgery waiting lists, Maori health development, child health and mental health. New Zealand First negotiated free general practitioners visits and pharmaceuticals for all children under six years of age, no more part

¹¹⁹ ‘Diabetes (a brief outline of the focus of some of the planning for purchasing and activities)’, in NPAD Working Party Agenda Papers, 15 November 1995, Personal Collection of A/Prof Tim Kenealy; Tukuitonga; McLeod; Dermot McNerney, *Diabetes Research Report*, Midland RHA, 1996; Minutes of the Meeting of the NPAD Working Party, 15 November 1995, Personal Collection of A/Prof Tim Kenealy.

¹²⁰ Ministry of Health, *Issues Around a National Plan of Action for Diabetes: A Discussion Document*, Wellington, 1996.

¹²¹ ‘Analysis of NPAD Submissions’, Personal Collection of A/Prof Tim Kenealy.

¹²² CHEs were renamed Regional Hospital and Community Services to reflect this change of emphasis.

charges on hospital outpatient services and the removal of means testing for elderly and long-stay hospital care.¹²³

A Steering Group advising on implementation issues for the new policies determined significant culture change would need to occur for health providers to move away from a competitive focus on reducing costs, towards more co-operative practices focused on improving health.¹²⁴ Furthermore, the Minister of Health, National's William (Bill) English, and the Associate Minister of Health, New Zealand First's Neil Kirton, had high profile political disagreements which caused major distractions for meeting health policy objectives; Kirton was fired in September 1997.¹²⁵ The disagreements between National and New Zealand First extended beyond health and the coalition collapsed completely in August 1998.

The uncertainty generated under the coalition government created fresh doubts about the resources and priority diabetes would have in the new health system. The Ministry's Diabetes Team Project Manager, Tina McNicholas, explained to the Diabetes Advisory Group that 'the environment the Ministry is now operating in is different from the one at the start of the plan's development': the Ministry was still unclear about its role in relation to the new national funding agency replacing the RHAs, called the Transitional Health Authority. She relayed that it was unlikely there would be any new funding to implement the plan and that it should be used more as 'a point of leverage'.¹²⁶ NZSSD President and Advisory Group member Dr Rick Cutfield reported to colleagues that the Ministry 'seem genuinely frustrated by their change of circumstances and priorities'.¹²⁷ Diabetes would no longer be an ongoing

¹²³ Gauld, p.145.

¹²⁴ *Implementing the Coalition Agreement on Health: the Report of the Steering Group to Oversee Health and Disability Changes to the Minister of Health and the Associate Minister of Health*, Wellington, 1997.

¹²⁵ Toni Ashton, 'The Health Reforms: to Market and Back?', p.151.

¹²⁶ McNicholas to Tim Kenealy, 6 March 1997, Personal Collection of A/Prof Tim Kenealy.

¹²⁷ 'NZSSD President's Report April 1997', Personal Collection of Dr Bob Smith.

project within the Ministry as it shifted significant resources into general child health initiatives.¹²⁸ The Ministry suggested that some diabetes work might be fundable through the Maori health development area; however, it was really up to the Transitional Health Authority.¹²⁹

Following these changes, in June 1997 instead of the NPAD, the Ministry released *Strategies for the Prevention and Control of Diabetes in New Zealand (Strategies for Diabetes)*. The eleven key strategies focused on reconfiguring health services away from acute to preventive care, issues of education, service co-ordination, accessibility and workforce development. This included the establishment of locally run, but nationally compatible information systems for patient monitoring and collecting epidemiological data, the integration of education with treatment and the integration of primary and secondary care.¹³⁰ The strategies promoted intra/intersectorial collaboration in health promotion and community development with a special focus on Maori and Pacific communities. Such recommendations aligned with the coalition government's policy directions to reduce competitive behaviour. However, the document detailed an expectation of 'funding constraints', pessimism over the ability to induce collaboration and uncertainty about the new roles of central health agencies with implementation largely left up to the wider health community and successor of the Transitional Health Authority.¹³¹ It took two years for the Transitional Health Authority to convert into the Health Funding Authority (HFA) and it was not operational until the end of 1998.¹³²

¹²⁸ Jenny Reid, 'Food and nutrition policy: a personal perspective of food and nutrition policy in New Zealand', *Proceedings of the Conference of the New Zealand Dietetic Association*, 2, September 1997, pp.13–15.

¹²⁹ McNicholas to Tim Kenealy.

¹³⁰ Ministry of Health, *Strategies for the Prevention and Control of Diabetes in New Zealand*, Wellington, 1997, p.9.

¹³¹ *Ibid.*, pp.4, 20–21.

¹³² Gauld, pp.148–53.

In a general climate of public distrust and uncertainty in the health sector, some on the Diabetes Advisory Group spoke openly of what they perceived as government inertia towards addressing New Zealand's diabetes 'epidemic'. The Group's Chairman and President of DNZ, John Denton, wrote in *Breakthrough*, 'the diabetes epidemic sweeping the country just should not happen in the 1990s and, had diabetes been a contagious disease, would never have been allowed to happen'.¹³³ Dr David Simmons concluded that waiting for government action was 'a path to inertia', telling a Royal Australasian College of Physicians meeting that his 'local community [South Auckland] knows there is an epidemic' and that the diabetes plan 'should not be allowed to gather dust'.¹³⁴ Meanwhile, the tragic case of Rau Williams also brought attention to the diabetes epidemic; Northland Health denied kidney dialysis treatment to the sixty-three-year-old diabetes patient with end stage renal failure in September 1997, which sparked public outrage over apparent service rationing. Williams died the following month. The television programme *Assignment* revisited the case during a diabetes special, entitled 'The slow killer' in October 1998.¹³⁵ The *New Zealand Herald* reported two months later that Simmons, 'one of New Zealand's top diabetes specialists' was leaving to work in Australia because the 'diabetes epidemic here is not being addressed'.¹³⁶

The government minimised the national significance of diabetes by framing it as a local problem for some communities. This was the argument the Minister of Health Bill English made on the aforementioned *Assignment* programme. Similarly, at a meeting in November 1997 when the Presidents of the NZSSD, Diabetes Youth and DNZ had asked English for a national diabetes taskforce to implement *Strategies for Diabetes*, he relayed that his

¹³³ John Denton, 'From the president – conference and awareness week makes for busy time', *Breakthrough*, 9, 2, Winter 1997, p.3.

¹³⁴ *Newsweet*, June 1997, p.2; Patterson, 'Will government act on diabetes?'

¹³⁵ 'The slow killer', *Assignment*, 8 October 1998, TVNZ.

¹³⁶ 'Diabetes epidemic ignored: expert – suffering "avoidable"', *New Zealand Herald*, 4 December 1998, p.1.

‘government believed that we should be looking for local solutions to local problems’.¹³⁷

While this was in accord with *Strategies for Diabetes* community development principle of local groups creating solutions for their own people, English said nothing on the issues that most concerned diabetes groups: how these solutions would be resourced and co-ordinated.¹³⁸

The diabetes organisations’ leaders left the meeting with the message that neither the Ministry of Health nor HFA were prepared to ensure funding or establish a national taskforce to co-ordinate diabetes initiatives; they would have to continue to push for change at the local level.

Therefore, from 1995 to 1998 political disruption to the health system resulted in the proposed NPAD being transformed into an unfunded and unenforceable series of recommended strategies. At the national level, diabetes appeared to be no longer a public health priority, even though some claimed that diabetes in New Zealand now constituted an epidemic.

Diabetes 2000

Released in March 2000, the HFA’s *Diabetes 2000* concluded that ‘New Zealand must establish a world-class comprehensive service for people with diabetes. It must include prevention, early detection, and effective treatment at every stage of the development of this disease. We cannot afford to fail.’¹³⁹ The National government had assured an additional \$5 million dollars per annum diabetes funding to implement this service. What had happened to the apparent government inertia towards the diabetes epidemic?

In *Strategies for Diabetes*, the Ministry of Health endorsed the targets of the *New Zealand Declaration*, which focused on cutting diabetes complication rates, but expressed a need to

¹³⁷ ‘NZSSD President’s Report for 1997/1998’, Personal Collection of Dr Bob Smith.

¹³⁸ Ibid.

¹³⁹ HFA, *Diabetes 2000*, Wellington, 2000, p.39.

collect baseline data and integrate systems before it could assess any progress.¹⁴⁰ In the interim, it set five-year targets to reduce the annual age standardised mortality rate to 8 or less per 100,000 total population by the year 2002 and the Maori rate to 30 per 100,000.¹⁴¹ These targets were widely acknowledged as unreliable measures due to under-reporting of diabetes mortality statistics and, in any case, in 1998 the Ministry determined them unachievable.¹⁴² In mid-1998, the Ministry funded the Otago Diabetes Team, Comprehensive Health Services Ltd (on Auckland's North Shore), Mangere Health Trust, and South Auckland Diabetes Project to undertake a joint Diabetes Health Information Project. The project investigated the dataset, privacy and logistical issues for systems to improve co-ordination and monitoring of patient care and data collection in primary and secondary care, in order 'to facilitate national planning and action for the control of diabetes'.¹⁴³

The HFA also began developing an integrated care policy in 1998, which included pilot diabetes projects. Integrated care was a goal of disease management approaches for common chronic conditions, pursued in the context of health reforms in the Western world in the 1990s. Essentially, it involved measures to better connect, structure and evaluate primary and secondary health providers to improve quality of care for the individual patient in the belief this produced better population health outcomes and lowered costs.¹⁴⁴ These were well-established ideals in diabetes management as Aaron Mauck and Martin Moore's respective doctoral research on the United States and British experience have documented.¹⁴⁵ In the New Zealand context, these ideals could be seen underpinning the evolution of educational services

¹⁴⁰ Ministry of Health, *Strategies for the Prevention and Control of Diabetes*, p.14.

¹⁴¹ Ibid.

¹⁴² Ministry of Health, *Progress on Health Outcome Targets*, Wellington, 1998, pp.212–17. It is not as if this was a new problem: see Chapter One.

¹⁴³ *Newsweek*, June 1998, p.7; Nicholas Wilson, Osman Mansoor and David Simmons, 'Diabetes in New Zealand – better information needed', *NZMJ*, 112, 1089, 11 June 1999, p.207.

¹⁴⁴ The approach was particularly associated with managed care in the United States: Dr Sandy Dawson, Interviewed by C.E. Harper, 17 August 2011.

¹⁴⁵ Mauck; Martin Moore, 'A Question of Control? Managing Diabetes and its Professionals in Britain, 1910–1994', PhD thesis, University of Warwick, 2014.

and service guidelines for shared care in the 1970s and 1980s, discussed in Chapters Four and Five of this thesis. In 1997, the Southern RHA funded an integrated care initiative, the Otago Diabetes Team Project, which contracted the local diabetes society to employ and provide a base for a care co-ordinator.¹⁴⁶ The same year North Health RHA funded both Comprehensive Health Services Ltd and Mangere Health Trust projects that involved collaboration with various service providers in both prevention and management of diabetes in their respective patient populations.¹⁴⁷ The HFA called for tenders for initiatives that could become national pilot demonstration projects for its integrated care policy in 1998 and selected Comprehensive Health Services and Mangere Health Trust to continue developing their schemes.¹⁴⁸

Diabetes was also on the HFA agenda due to a cabinet decision to fund a Hepatitis B screening programme. Since 1992, the Hepatitis Foundation's Alexander (Sandy) Milne, an 'unabashed screening enthusiast', had promoted population screening of Maori and Pacific people for diabetes as an adjunct to Hepatitis B carrier screening, as both diseases were common and under-diagnosed in these groups.¹⁴⁹ The idea had won little support from both diabetes specialists and Maori at the time; the former worried about the ability of downstream services to cope, and the latter the ineffectiveness of existing treatment, based on weight reduction and tablets, out of context of Maori values. According to a history of the Foundation, after a presentation by high profile diabetes specialist Professor Bob Elliott to a 'packed meeting co-hosted by O Ngati Awa' in Whakatane in the Eastern Bay of Plenty in

¹⁴⁶ A.J. Gilles, 'The Otago Initiative: expanding the quality of diabetes care', *Breakthrough*, Spring 1997, pp.11–12.

¹⁴⁷ Health Services Research Centre, *National Demonstration Integrated Care Pilot Projects: Diabetes Management, Mangere, Final Evaluation Report*, Wellington, 2001, p.6; Health Services Research Centre, *National Demonstration Integrated Care Pilot Projects: Diabetes Management, Comprehensive Health Services, North Harbour, Auckland, Final Evaluation Report*, Wellington, 2001, p.6.

¹⁴⁸ These, like the other seven demonstration projects, were focused on changing service delivery through tools like registers and audits, clinical pathways and referral guidelines, a care co-ordinator (Mangere), special training of practice nurses and relationship building with Maori providers.

¹⁴⁹ Deborah Jowitt, 'Government Policy Relating to Hepatitis B in New Zealand 1970–2005', PhD thesis, University of Auckland, 2010, p.254

June 1998, there was now ‘unanimous support’ for a combined screening programme. Greater recognition amongst community members of diabetes’ damaging effects had encouraged a change of attitude. The programme would start in the Bay of Plenty and expand as funding allowed.¹⁵⁰ Local Lions clubs would fund the diabetes tests. Following this, and despite health officials’ preference for a pilot study, Milne’s campaign of lobbying Maori MPs succeeded in gaining public funding for a screening programme for Hepatitis B in high-risk groups.¹⁵¹ The HFA called for tenders in January 1999 and invited comments on the proposal of adding diabetes tests.

When Wyatt Creech became Minister of Health in February 1999, he was keen to restore public faith in the health system in time for the election at the end of the year. The President of the NZSSD wrote to Creech urging the enactment of *Strategies for Diabetes*, following the recent release of Australia’s federally funded implementation plan for its diabetes control strategy. Creech replied that ‘it is an area we need more action’ and that the HFA were working on the matter.¹⁵² The HFA’s Clinical Advisor at the time, Dr Sandy Dawson, has recalled that early in 1999 the National government was ‘looking around for what investments they could make in health that perhaps might help them win the election’.¹⁵³ Creech decided to earmark \$10 million per annum of new funding for disease management programmes and requested the HFA determine how to prioritise it. The three diseases the HFA came up with were heart disease, asthma and diabetes. Dawson recommended to the HFA Chief Executive Officer David Moore that the major focus should be on diabetes as the increasing age, obesity

¹⁵⁰ Vivien Edwards, *Battling the Big B: Hepatitis B in New Zealand*, Wellington, 2007, pp.163, 87–91,175–83. Bob Elliott had a high profile due to his research into type 1 diabetes prevention; firstly in the late 1980s and early 1990s with regards to proposed national screening of children and treating those with certain antibodies with nicatoride, and secondly in the latter 1990s with the hypothesis that a protein in cow’s milk commonly drunk in New Zealand, was an environmental trigger for the onset of type 1 diabetes. The latter drew significant media comment due to the potential damage to New Zealand’s dairy industry.

¹⁵¹ Jowitt, pp.213–55.

¹⁵² Peter Moore, ‘NZSSD President’s Report 1998–99’, Personal Collection of Dr Bob Smith.

¹⁵³ Dr Sandy Dawson, Interviewed by C.E. Harper, 17 August 2011.

and shifting ethnic profile of the country was creating an accelerating epidemic requiring a complex response to ‘get ahead of the curve’.¹⁵⁴ In May 1999 Creech released *The Government’s Medium-Term Strategy for Health and Disability Support Services*, which set out twelve goals for the next three to five years and assured a level of stability and autonomy for the health sector in developing policies.¹⁵⁵ This document indicated that the HFA and Ministry of Health would collaborate ‘to further develop and implement strategies that address illnesses that cause major health problems for significant groups of New Zealanders’; diabetes was the only identified illness.¹⁵⁶

The first issue for the Ministry and HFA to deal with was the Hepatitis Foundation’s diabetes screening proposal. As discussed in Chapter Three, since the 1970s health officials had been doubtful about the value of community-based screening for diabetes; now that there was a dedicated diabetes budget, the motivation to assess cost benefits was even stronger. By this time, there was strong evidence that good metabolic and blood pressure control, regular foot checks and retinal screening could prevent or halt diabetes complications, thus supporting asymptomatic intervention. However, prominent Pacific physician and health researcher Dr Colin Tukuitonga argued that the proposal was still ‘unethical under WHO guidelines’. He cited inadequacies in current care, such as two-year waiting lists for retinal screening, lack of support for general practitioners in high-risk areas, and insufficient nursing time for education. HFA Services Strategy Manager Dr Win Bennett had apparently come to agree that the ‘superficial attractiveness’ of a cheap add-on test needed to be weighed against such considerations.¹⁵⁷ *Strategies for Diabetes* recommended opportunistic screening based on risk factor profile, but this could ‘only be justified as part of a lifestyle intervention programme

¹⁵⁴ Ibid.

¹⁵⁵ Wyatt Creech, *The Government’s Medium-Term Strategy for Health and Disability Support Services*, Wellington, 1999, p.2.

¹⁵⁶ Ibid., p.12.

¹⁵⁷ Daryl McIntosh, ‘Questions over screening ethics’, *New Zealand Doctor*, 3 March 1999, p.9.

which can reduce risk factors for individuals whether they screen positive or not'.¹⁵⁸ For those with impaired glucose tolerance (IGT) the 'treatment' and 'prevention' – diet and exercise – were the same, so it appeared more cost-effective to focus resources on healthy lifestyle promotion; this also would reduce the harm of false negatives.

The HFA declined to fund the add-on proposal, which led to a series of articles in the press highly critical of health officials' attitudes. Milne and supporters argued the Hepatitis B programme was the perfect opportunity to reach high-risk groups at minimal cost; once people knew their diagnosis they would be more motivated to make lifestyle changes. New Zealand First leader Winston Peters attacked the government for ignoring a 'diabetes bomb'.¹⁵⁹ Health officials argued that a one-off screening for diabetes was inappropriate, as those at risk of diabetes needed regular re-examination, and that the proposal could not ensure appropriate treatment services would follow detection. There was also no expert consensus on the proposed screening test, HbA1C. Moreover, the thrust of *Strategies for Diabetes* in relation to addressing Maori diabetes was for Maori-led health promotion.¹⁶⁰

The Hepatitis Foundation proceeded to screen 10,000 people, mostly Maori, in the Eastern Bay of Plenty using charitable funding; they referred those with abnormally high HbA1C to their general practitioner, and gave those with mildly elevated levels written advice on

¹⁵⁸ Ministry of Health, *Strategies for the Prevention and Control of Diabetes*, pp.16–17.

¹⁵⁹ For example, see 'New health measures ignore diabetes problem, says Peters', *Waikato Times*, 26 May 1999, p.9; Jon Stephenson, 'Government ignores diabetes bomb', *National Business Review*, 25 June 1999, p.7; Jon Stephenson and Jock Anderson, 'Health mandarins duck diabetes crisis' *National Business Review*, 25 June 1999, p.1; Jon Stephenson, 'Government's diabetes policy comes under fire', *National Business Review*, 2 July 1999, p.13; Vivien Edwards, 'Cold shoulder for diabetes screening', *New Zealand General Practitioner*, 14 July 1999, pp.1–2.

¹⁶⁰ Felicity Dumble, *Diabetes Screening as an Adjunct to the Hepatitis B Screening Programme*, HFA Wellington, 1999; Dr Karen Poutasi, 'Better ways will handle rising number of diabetics', *National Business Review*, 2 July 1999; Tracy L. Ellison, Robert Elliot and Simon A. Moyes, 'HbA1c screening for undiagnosed diabetes in New Zealand', *Diabetes/Metabolism Research and Reviews*, 21, 1, January/February 2005, pp.65–70.

lifestyle, but there was insufficient funding for follow-up.¹⁶¹ The HFA went on to fund an evidence-based review of screening for Type 2 diabetes, which led to the introduction of systematic diabetes and IGT screening as part of cardiovascular risk assessments in general practice.¹⁶²

A guiding principle of disease management strategies was to look across the disease-state spectrum for where resources would produce the greatest benefit; this underpinned the HFA's response to the government's *Medium-Term Strategy*. After consultation with the Ministry, the HFA decided there was no need for a new strategy and began planning for implementation of *Strategies for Diabetes*. The Crown's 1999/2000 funding agreement with the HFA allocated \$5 million per annum, half of the total disease management funding, for a three-year diabetes purchasing programme that built on the diabetes demonstration pilots and the Diabetes Health Information Project.¹⁶³ In October 1999, the HFA drew together representatives from DNZ, Te Roopu Mate Huka, health funding, management, specialist and primary care to form a National Diabetes Working Group (NDWG). The NDWG would oversee 'development of a disease management approach to diabetes from primary prevention, through to tertiary treatment' and report annually to the Minister of Health.¹⁶⁴ The HFA also began establishing Regional Diabetes Teams, with a strong consumer component and special focus on Maori and Pacific needs, to identify and monitor regional services.¹⁶⁵ By the end of the year, implementation was imminent for the first of *Strategies for Diabetes*

¹⁶¹ Edwards, p.180.

¹⁶² Tim Kenealy, Geoff Braatvedt and Robert Scragg, 'Screening for Type 2 diabetes in non-pregnant adults in New Zealand: practice recommendations', NZMJ, 115, 1152, 26 April 2002, pp.194–6; New Zealand Guidelines Group, *The Assessment and Management of Cardiovascular Risk: Evidence Based Practice Guideline*, Wellington, December 2003.

¹⁶³ The money was from the government's sustainable funding increase and would continue indefinitely: 'HFA Presentation to the National Diabetes Working Group', 1999, Personal Collection of A/Prof Tim Kenealy.

¹⁶⁴ National Diabetes Working Group Annual Report 1999–2000, Personal Collection of A/Prof Tim Kenealy; National Diabetes Working Group Annual Report 2000–01, p.4, Personal Collection of A/Prof Tim Kenealy.

¹⁶⁵ These became known as Local Diabetes Teams under the implementation plan discussed below: see HFA, *Diabetes 2000*, p.3.

recommendations – a free annual check, complications screening and treatment review in primary care and referral to specialist services if indicated.

Although National did not win the election in November 1999, Labour maintained the funding allocation and in March 2000, the HFA released an implementation plan, *Diabetes 2000*.¹⁶⁶ The plan detailed resource allocation and activities for the next three years. Half of the funding went towards the free annual review ('Get Checked') programme.

Complementing 'Get Checked' were new education resources in Pacific languages, a Maori mobile nursing service and practice guidelines for primary health workers, and plans to devolve funding to Maori and Pacific health providers for their own programme development. Additionally, funding went into more equitable diabetes service coverage across the country, more eye screening and education, database development and targeted free glucose monitors. Ten per cent of the funding went into applied research projects in primary prevention of Type 2 diabetes in those with IGT.¹⁶⁷ The stated objective of the plan was 'removing the inequality of health outcome for Maori and Pacific Island people'.¹⁶⁸

Thus, after a decade of uncertainty and underfunding in the health system a new National Minister of Health Wyatt Creech recognised the importance of health policy in an election year, devoted dedicated funding to diabetes management. Moreover, he left health officials to decide how best to allocate it. Despite considerable political pressure for a diabetes screening campaign, the approach which officials chose followed the previous advice of diabetes health

¹⁶⁶ HFA, *Diabetes 2000*. The new Labour government would reform the health sector again, creating elected District Health Boards. It prioritised reducing Maori health inequalities, re-established national health goals and implemented a primary care strategy, which the HFA had already been working on. The diabetes plan was developed to align with the changes but did not differ significantly from the original strategies, although some specialists felt there was a lack of consultation and questioned the 'primary care agenda': see Peter Moore, 'NZSSD President's Report 1999–00', Personal Collection of Dr Bob Smith.

¹⁶⁷ 'HFA campaign helps people with diabetes', Media Release embargoed until 30 June 2000, in *Get Checked Diabetes Aotearoa: National Diabetes Campaign* (pack for general practitioners), Personal Collection of A/Prof Tim Kenealy; Dr Sandy Dawson, Interviewed by C.E. Harper, 17 August 2011.

¹⁶⁸ HFA, *Diabetes 2000*, p.39.

professionals and consumer groups outlined in *Strategies for Diabetes*. In turn, this reflected broad international trends in integrated diabetes management, which began in the 1970s and gained greater impetus in New Zealand with the higher political profile of Maori and Pacific health in the 1990s.

An alternative approach: diabetes and the ‘obesogenic environment’

The policy focus on integrated diabetes management had not excluded the development of an alternative approach. Concerns about the ‘obesogenic environment’ resulted in calls for more interventionist public health action to protect the entire population from the environmental contributors to diabetes. Advocates of this new public health approach to diabetes based their case on a re-conceptualisation of obesity and lessons from tobacco control policy.

In the 1980s, Christchurch diabetes expert Professor Donald Beaven was a vocal crusader in espousing a public health agenda on obesity and diabetes comparable to that emerging amongst anti-smoking activists. Virginia Berridge has described how in Britain in the 1970s anti-smoking lobby group ASH played a key role in pressing for taxation as a tool to alter smoking behaviour. While the Chancellor introduced differential taxes on goods like cigarettes and alcohol as part of managing an economic crisis, Berridge noted that ‘the health case for taxation [also] started to be accepted’.¹⁶⁹ In New Zealand, the Minister of Health introduced a tax on tobacco to fund community health projects in 1977 and Beaven had utilised this funding in setting up the Christchurch Diabetes Centre.¹⁷⁰ Beaven first proposed that an ‘honest government’ would tax sugar in 1975, and in the mid-1980s he called for taxes on televisions, beer and sugar, primarily as a way to fund health services, but also as a way to influence behaviours which he suggested were increasing the prevalence of obesity and

¹⁶⁹ Virginia Berridge, *Marketing Health: Smoking and the Discourse of Public Health, 1945–2000*, Oxford, 2007, p.204.

¹⁷⁰ See Chapter Four.

diabetes.¹⁷¹ He publicly denounced New Zealand's political culture for promoting obesity through its acquiescence to powerful national industries – the breweries, sugar refineries and producer boards.¹⁷² In line with ASH's attempts to expose tobacco industry tactics and restrict its activities, Beaven's agenda was to reveal that industry interests were holding back school and public health education on nutrition.

Epidemiological findings on obesity rates released in the 1990s inspired further discussion of using economic levers as preventive tools. Auckland Medical School epidemiologist Rod Jackson reported in 1995 that his team's long-term study of cardiovascular risk factors found Pakeha in Auckland were 5 per cent fatter than a decade previously. The proportion of men categorised as overweight or obese (having a Body Mass Index over 25) had risen from 52.8 per cent in 1984 to 64.2 per cent in 1993-4, while the percentage of women rose from 36.5 per cent to 44.9 per cent.¹⁷³ Tobacco use, however, had gone down, which Jackson linked to increased regulation and price rises during this period. The *Dominion* reported that Jackson would be publishing a paper suggesting that a tax on high-fat foods and subsidies for low-fat foods was the answer to obesity.¹⁷⁴

The non-governmental sector also promoted a new approach to obesity prevention. In 1996 Agencies for Nutrition Action (ANA), produced two important documents: their *Healthy Weight New Zealand* strategy and a scientific paper estimating the health care costs of

¹⁷¹ 'We're a nation of over-eaters says Prof Beaven', *N.Z. Diabetic Review*, 13, 2, May 1975, p.19. Example newspaper clippings are in D. W. Beaven Papers, Accession #195, 36821, Macmillan Brown Library, Canterbury (MBLC). Beaven's political campaigning on diabetes is discussed in Chapter Five.

¹⁷² D.W. Beaven, 'Failure of school health education: cultural neglect or political rigidity', *NZMJ*, 94, 693, 14 October 1981, p.268.

¹⁷³ Agencies for Nutrition Action, *Healthy Weight New Zealand: Taumaha Tika Aotearoa*, May 1996, p.2; P. Metcalf, R. Scragg, D. Schaaf, L. Dyal, P. Black and R. Jackson, 'Trends in major cardiovascular risk factors in Auckland, New Zealand: 1982 to 2002-3', *NZMJ*, 119, 1245, 17 November 2006, URL:

<http://www.nzma.org.nz/journal/119-1245/2333/>, accessed 6 May 2013.

¹⁷⁴ 'Fitting your genes', *Dominion*, 31 July 1995, p.11.

obesity-related health problems (like diabetes) in New Zealand.¹⁷⁵ *Healthy Weight New Zealand* used Jackson's study to argue that 'there has been an increase in obesity and overweight over the last decade despite education'.¹⁷⁶ It called for a focus on 'prevention using a population approach' (supporting maintenance of a healthy weight across the nation) rather than the predominant treatment approach (encouraging individuals to lose weight and fat) claiming the success rate of the latter was low and methods often costly.¹⁷⁷ New data calculated the risk of developing NIDDM as 50–100 fold higher in the obese, a far greater risk than a life time of heavy smoking contributed to heart disease (2–3 fold) or lung cancer (20–30 fold).¹⁷⁸ ANA highlighted its key argument in bold: '**Essentially the prevention of NIDDM is the prevention of obesity.**'¹⁷⁹ ANA's advocacy resulted in a government contract to consult on its strategy and also led to the Ministry of Health including adult obesity reporting in its annual goals and targets.¹⁸⁰

For health officials developing prevention policy on the linked issues of obesity and diabetes their model was the 1986 Ottawa Charter for Health Promotion. The Charter conceived solutions to non-communicable health problems as a matter of encouraging behavioural changes through the empowerment of individuals; however, it also put emphasis on 'healthy public policy' (ensuring that health considerations were a priority in all policy-making) and 'supportive environments' (generating living and working conditions that enhanced well-

¹⁷⁵ Heather Fear and Pauline Barnett, 'Holding fast: the experience of collaboration in a competitive environment', *Health Promotion International*, 18, 1, 2003, p.10; B. Swinburn, T. Ashton, J. Gillespie, B. Cox, A. Menon, D. Simmons and J. Birkbeck, 'The health care costs of obesity in New Zealand', *International Journal of Obesity*, 21, 10, October 1997, pp.891–6.

¹⁷⁶ Agencies for Nutrition Action, p.2.

¹⁷⁷ Ibid., p.3; D.M. Garner and S.C. Wooley, 'Confronting the failure of behavioural and dietary treatments for obesity', *Clinical Psychology Review*, 11, 6, 1997, pp.573–8. The focus on a healthy weight, as opposed to losing weight, was also in response to concerns about eating disorders and research that found children rated being obese more seriously than losing a limb. See also, Jenny Chamberlain, 'Once were waistlines: facing fat', *North and South*, November 1996, pp.66–76.

¹⁷⁸ 'Analysis of NPAD Submissions', p.12, Personal Collection of A/Prof Tim Kenealy.

¹⁷⁹ Boyd Swinburn, 'Agencies for Nutrition Action Proposed Relationship to Diabetes Forum and National Plan of Action for Diabetes', Agenda Papers for Diabetes Advisory Group Meeting, 9 July 1996, Personal Collection of A/Prof Tim Kenealy.

¹⁸⁰ Fear and Barnett, pp.10–11.

being). A key effect was that those in the public health field increasingly argued lifestyle was not only a matter of individual choice.¹⁸¹ Planning discussions for the NPAD were an explicit example of this.¹⁸²

Many of the submissions on the proposed NPAD focused on the need to strengthen public policy and environments to prevent NIDDM. Boyd Swinburn, the Medical Director for the National Heart Foundation (NHF), objected to a proposal for people with diabetes ‘to spread simple messages’ about healthy living and instead advocated ‘a focus on the environment’.¹⁸³ One RHA manager argued ‘the time is now right’ for the types of policies likely to meet ‘political resistance’ such as fat taxes.¹⁸⁴ Many pointed out that the major impediment to successful nutritional education was the cost of healthy foods and suggested removing the goods and service tax on fruits and vegetables.¹⁸⁵ Some voiced concern that low incomes limited healthy food choices and at the insidious marketing of corporations like McDonalds and Coca-Cola which sponsored schools in deprived areas. The President of Diabetes Northland called for regulatory control of the food industry and food labelling. The Chief Executive of the New Zealand Medical Association stressed that the ‘short term commercial interests of the food industry should not prevent national problem solving’.¹⁸⁶ Public health physician Nicholas Wilson argued that ‘the scale of the problem means major structural changes are needed’, including saturated fat taxes, carbon taxes, higher parking fees and more

¹⁸¹ More details on the Ottawa Charter and its impact on local diabetes interventions are covered in Chapter Seven.

¹⁸² Minutes of the Meeting of the National Plan of Action for Diabetes Working Party, 15 November 1995, p.4, Personal Collection of A/Prof Tim Kenealy.

¹⁸³ ‘Analysis of NPAD Submissions’, p.3.

¹⁸⁴ *Ibid.*, p.13.

¹⁸⁵ *Ibid.*, p.18.

¹⁸⁶ *Ibid.*, p.13.

cycle-ways.¹⁸⁷ Swinburn highlighted the need to ‘increase resources for analysing and counteracting [the] obesogenic environment’.¹⁸⁸

Swinburn was a key figure driving research and public discussion on the obesogenic environment in the late 1990s. Swinburn had specialised in endocrinology, and it was only during his time as Medical Director of the NHF (1993-2000) that he shifted his focus to public health research on obesity.¹⁸⁹ He has recalled that after spending time searching inside the body, his scientific interest in finding the root cause of diabetes had begun to lead him ‘upstream’ in the causation chain to the environment. As he had no formal public health training, he noted that he learned much ‘on the job’ with the NHF.¹⁹⁰ Swinburn and colleagues began using the term the ‘obesogenic environment’ to describe the ‘fat producing’ modern industrialised environmental conditions that promoted sedentary behaviour and the easy accessibility and palatability of high fat, energy dense foods.¹⁹¹ In their view, environmental change was the only feasible response to control obesity and diabetes.¹⁹²

A novel idea at the time, in many ways this was a continuation of the ‘new public health’ movement, which had emerged in the 1980s. The new public health was a return to the traditional public health developed out of mid-nineteenth century epidemiological studies of infectious diseases that focused on improving environmental conditions; however, it now encompassed modern health issues from road accidents to passive smoking. Thus, comparable responses – from regulating the food supply to urban planning to include more cycle-ways

¹⁸⁷ Ibid., p.18.

¹⁸⁸ Ibid., p.19.

¹⁸⁹ Boyd Swinburn, Interviewed by C.E. Harper, 5 March 2013.

¹⁹⁰ Ibid.

¹⁹¹ Boyd Swinburn, Garry Egger and Fezeela Raza, ‘Dissecting obesogenic environments: the development and application of a framework for identifying and prioritizing environmental interventions for obesity’, *Preventive Medicine*, 29, 6, December 1999, p.564.

¹⁹² B. Swinburn and G. Egger, ‘An ecological approach to the obesity pandemic’, *British Medical Journal*, 315, 7106, 23 August 1997, p.477.

and parks – could potentially cut population obesity. In 1999 Swinburn began developing a framework for identifying and prioritising these types of environmental interventions for obesity.¹⁹³ He presented progress on this work at the Western Pacific Region IDF meeting in Sydney that year, which had an important effect in stimulating diabetes organisations to take up the new public health approach.¹⁹⁴

At the turn of the century, diabetes professionals were looking afresh at their role in obesity prevention. Swinburn has recalled that there was a lot of optimism in the public health community about achieving an environmental focus on obesity under the new Labour Prime Minister Helen Clark due to her reputation for being prepared to take on the tobacco industry when she was Minister of Health in 1989–90.¹⁹⁵ Swinburn was a keynote speaker at the obesity-themed NZSSD conference in August 2000, receiving the adulation of its new President Robyn Toomath. Toomath, an endocrinologist in Wellington, described him as ‘inspirational’ and wished ‘we could just snap our fingers and bring his ideas into reality’.¹⁹⁶ She continued, ‘I wonder if at times he felt like a one-man band, and whether the Society [NZSSD] should have been more supportive of him and his public health focus.’¹⁹⁷ Not long after this, Toomath and new DNZ Chief Executive (and former anti-smoking strategist) Sarah Thomson decided to form an advocacy group focused on prevention of obesity in children.

Childhood obesity became a significant public concern in the late 1990s. The ANA’s *Healthy Weight New Zealand* had included estimates that up to 30 per cent of New Zealand children

¹⁹³ Swinburn: Measuring the Obesogenic Environment (feasibility study), 1997–99, YCBN 5815 A1752 27/k 94/477, ANZA.

¹⁹⁴ Robyn Toomath ‘Genes vs. environment’, *Newsweet*, p.5, Personal Collection of Dr Bob Smith.

¹⁹⁵ Boyd Swinburn, Interviewed by C.E. Harper, 5 March 2013.

¹⁹⁶ Robyn Toomath, ‘Editorial’, *Newsweet*, September 2000, p.1. Swinburn was about to take up a full-time research position in population obesity prevention in Australia having failed to get funding in New Zealand: see ‘Top health expert joins brain drain’, *Sunday Star Times*, 9 September 2000.

¹⁹⁷ Toomath, ‘Editorial’, p.1.

were obese.¹⁹⁸ In 1997, the Ministry of Health proposed an inquiry into childhood obesity which public health advocates welcomed, as there was a lack of robust statistical data on the issue. Swinburn has argued this ‘data deficit’ made it difficult to counter the food industry’s political influence that had helped shut down the PHC.¹⁹⁹ By 1999, local and international experts warned of increasing Type 2 diagnoses, previously the reserve of the middle-aged and elderly, in adolescents. Media reports singled out direct marketing of fast food to children, computers and television viewing as responsible.²⁰⁰ Toomath and Thomson latched onto these concerns, establishing ‘Fight the Obesity Epidemic’ (FOE) in 2001 to ‘change our obesity-promoting environment’. FOE would become a high profile lobby group in the early 2000s advocating an end to the promotion of unhealthy food to children, ‘traffic light’ food labelling systems, and tax changes to make healthy food more affordable relative to less healthy options.²⁰¹

In brief, the late 1990s witnessed the emergence of an environmentally focused ‘new public health’ understanding of obesity in relation to diabetes prevention. Under this model, the food industry would stand to become the equivalent of big tobacco.²⁰² At the turn of the century, hoping for a favourable political response under the new Labour government, proponents of intervention into the obesogenic environment focused their efforts on developing an evidence and advocacy base.

¹⁹⁸ Agencies for Nutrition Action, p.2

¹⁹⁹ ‘Dietitians back study on childhood obesity’, *Dominion*, 18 September 1997, p.21; Boyd Swinburn, 5 March 2013, Interviewed by C.E. Harper.

²⁰⁰ ‘TV obesity link seen’, *Waikato Times*, 20 August 1997, p.19; Christopher Moore, ‘TV ads feeding obesity’, *Press* (Christchurch), 28 October 1997; Keith Perry, ‘Diabetes curse on track to NZ’, *New Zealand Herald*, 16 February 1999; ‘Kiwi kids face glut of fat-food ads on TV’, *Dominion*, 2 December 1998; ‘Young TV habits cause for alarm’, *New Zealand Herald*, 12 October 1999.

²⁰¹ <http://foe.org.nz/about-foe/> accessed 21 September 2014.

²⁰² Thomson noted FOE consciously avoided an ‘adversarial’ approach to industry. However, Toomath saw it as a ‘staunch outlying group’ working against the dominant message from the food industry that promoting physical activity was the best solution: Sarah Thomson, Interviewed by C.E. Harper, 13 March 2013; Robyn Toomath, Interviewed by C.E. Harper, 11 March 2013.

Conclusion

In the 1990s, a 'new health environment', brought both challenges and opportunities to dealing with diabetes, which varied at the individual, organisational and policy levels.

For people with diabetes the targeted, user-pays approach to health services not only had a considerable financial impact, but also was, in some cases, a danger to their health.

Contradicting the government's stated intentions, these policies most negatively affected families of children with Type 1 and Maori and Pacific people with diabetes. In the early 1990s, these groups of people formed new advocacy organisations, in part, because of concerns about the costs of diabetes care.

For diabetes organisations, the government's focus on the voluntary sector and responsiveness had effects that were more positive. At a time DNZ was facing a real threat of dissolution, government contracts allowed it to become a self-sustaining national service provider for people with diabetes. Although diabetes organisations lobbied against many aspects of the health and welfare reforms, their underlying self-help philosophy sat well with the values government wished to promote. Government contracts also brought more attention to Maori and Pacific problems with Type 2 diabetes. The formation of Te Roopu Mate Huka was an example of the alignment of the government's neoliberal agenda and Maori pursuit of autonomy and empowerment in the 1990s. The formation of Diabetes Youth, however, partly reflected concerns about the shifting focus of government, DNZ and the media towards Type 2 diabetes.

For diabetes policy, the government's health reforms had a complex effect on its development and direction. Since the 1980s, both international and New Zealand networks of experts, consumer groups and officials promoted an integrated model of prevention and control

focused on systemising and monitoring education and care to ameliorate the financial and social costs of diabetes complications. Associate Health Minister Katherine O'Regan took an active interest in diabetes and followed PHC and consumer groups' recommendations in proposing a National Plan of Action for Diabetes. Further reforms to the health system, funding austerity and changing ministerial appointments, however, delayed the action plan. By 1999, electoral concerns pushed another new Minister of Health, Wyatt Creech, to follow health officials' advice, allocating \$15 million over three years of dedicated new funding for diabetes management strategies. These strategies aimed to identify, screen and educate those at risk of diabetes and its complications, predominantly in primary care, and to improve population data collection to feed back into service improvement. Regional teams with a strong consumer element would be responsible for overseeing and identifying local needs. The HFA would target resources where there was most need – Maori and Pacific communities – and these communities would be encouraged to provide their own services.

Despite the government's overarching desire to limit health expenditure, the decision to fund these diabetes management strategies actually aligned with core government objectives that survived through the health reforms: refocusing the health system towards primary care, more efficient, responsive, targeted planning and resourcing, and Maori health development. By contrast, the emerging new public health approach to addressing the 'obesogenic environment' would entail heavier government intervention into the free market and implied that responsibility for diabetes lay with the food industry rather than individuals, the health services, and 'at-risk' communities. However, how were these at-risk communities dealing with diabetes? The next chapter turns to the distinctive approach to diabetes in one such community, South Auckland in the 1980s and 1990s.

CHAPTER SEVEN

‘Dealing to diabetes – the South Auckland approach’: empowering communities?

Diabetes emerged as a major public health issue in South Auckland in the 1980s. As an area with a large proportion of Maori and Pacific people and socio-economic deprivation, South Auckland had a ‘high-risk’ population for diabetes and its complications. For this population orthodox diabetes care was generally ineffective, inaccessible or unacceptable. As such, South Auckland communities developed new approaches to diabetes that would attract national attention. The Minister of Health, David Caygill, visited South Auckland in December 1987 where he witnessed six Maori and Pacific women at work who, he believed, had succeeded ‘where traditional medicine had failed, not only because they share the culture and values of their clients ... but also because their approach has not been a narrow medical one’. Caygill indicated that in an environment of competing claims for limited resources, services such as these women provided, offered the health system the ‘best value for money’.¹

This chapter explores the development of distinctive community responses to diabetes in South Auckland: Maori and Pacific lay community health workers in the 1980s and a community control plan and intervention project in the 1990s. These responses occurred at a time when successive governments sought to reform, reduce and target public spending on health and welfare. The ‘South Auckland approach’ to ‘dealing to diabetes’ can thus provide a useful lens on the contested meanings of community development in public health during this

¹ David Caygill, ‘The value of caring’, cutting in Appendix H, Community Development Committee Minute No.1449, 7 July 1988, Auckland Council Archives South (ACAS).

period.² In an era of dramatic state reforms, the question arises: was the ‘South Auckland approach’ about empowering communities or cutting costs?

South Auckland: ‘a unique social laboratory’

From the 1950s to 1980s the southern suburbs of Auckland, New Zealand’s most populous and industrialised city, expanded rapidly. As Auckland’s inner city suburbs underwent a process of gentrification, the young Maori and Pacific migrants who had flocked there to fill labour force gaps, moved south to new state housing subdivisions in Otara and Mangere.³ Public health workers soon noted signs of social and economic deprivation – overcrowding, illness and educational difficulties – which they attributed to the rapid growth of a youthful, transient and low-paid population in these housing estates that the government had established without adequate community infrastructure.⁴ Moreover, many Maori and Pacific people in the area lost their jobs in the economic downturn of the 1970s, which caused additional poverty. By this time, Maori and Pacific people made up 30 per cent of the South Auckland region as a whole and 57 per cent of the population of Otara, compared to 11 per cent nationally.⁵ In Otara, 56 per cent of the population were under 20 years of age, less than half owned their own home and only 4 per cent had a tertiary education.⁶ In the words of Donna Awatere, an educational psychologist and Maori activist who worked in the area in the 1980s, ‘some of the

² Juliet Ashton, ‘Dealing to diabetes – the South Auckland approach’, *Health*, 41, 2 April 1992, p.16.

³ Helen Laurenson, ‘Myths and the City: A Social and Cultural History of Auckland, 1890–1990’, PhD thesis, University of Auckland, 2010, pp.235–6.

⁴ David Haigh and Colin Dale, ‘Community Development within Local Government: the Early Years’, in Love M. Chile, ed., *Community Development Practice in New Zealand: Exploring Good Practice*, Auckland, 2007, p.78.

⁵ Mary Jane P. Reid, ‘Elective Report: Training Community Educators in Nutrition, Obesity and Diabetes’, 1981, p.8, Health Services Research Committee, 22 February 1982, YCBN 5805 9/b, Archives New Zealand, Auckland (ANZA); Department of Statistics, *New Zealand Population and Migration, 1977–78*, Part A Population, Wellington, 1979, p.3; New Zealand Health Statistics Centre, *Mortality and Demographic Data*, 1979, Wellington, 1983, p.2.

⁶ Reid, ‘Elective Report’. These statistics were from Rae West and Barbara Harris, *Health Needs Survey South Auckland 1978*, Auckland 1978.

worst socio-economic conditions' had fostered 'a unique social laboratory' for community development.⁷

The emergence of strong community identities and grassroots activity in South Auckland also aided community development. Broadly, community development involves a process of empowering communities to identify their own problems and find their own solutions with the intention that this will enable individuals to have more control over their own lives.⁸ For a new generation of Maori activists in the 1970s, influenced by international civil rights movements, and local concerns about social marginalisation in the cities, tikanga (culture and customs) and te reo Maori (the Maori language), of which many young urban Maori felt deprived, was a key source of such empowerment.⁹ Community activists responded to the high concentration of young Maori in South Auckland by advocating and fundraising for Maori cultural, educational and recreational facilities. In turn, this activity provided residents with new connections and pride in their suburbs.¹⁰ The growing Pacific population had similar concerns for their young people and a desire to maintain their cultural traditions.¹¹ From the mid-1970s, South Auckland communities established urban marae (meeting places), kohanga reo (language nests), churches, youth centres, libraries, schools and street gardens, often with the assistance of the local authority, the Manukau City Council (MCC).

The MCC had a strong commitment to community development and community health.

Community development practice draws on the community's own resources as much as

⁷ Donna Awatere and Maria Mareroa, *Te Koputu Taonga, Otara: An Emergent Model for Community Development*, Auckland, c.1985, unpaginated.

⁸ Anne de Lacey, *Community Development in Health Part Two: Two New Zealand Programmes*, Department of Health, Wellington, 1989, p.4.

⁹ Aroha Harris, *Hikoi: Forty Years of Maori Protest*, Wellington, 2004, p.15, 24–25, 48.

¹⁰ Ben Schrader, *We Call it Home: A History of State Housing in New Zealand*, Auckland, 2005, p.187.

¹¹ Olivia James, 'The Otara Health Story', in Kevin Dew and Anna Mattheson, eds, *Understanding Health Inequalities in Aotearoa/New Zealand*, Otago, 2008, p.185.

possible, supplemented with services and materials from the state or voluntary sector. The MCC began this work in 1966 when it appointed a Social Services Officer, the first such position for local government in New Zealand, to co-ordinate social assistance, promote new services, set up community groups and negotiate with central government for community facilities.¹² In the 1970s, the MCC collaborated with local health agencies and researchers to identify the extent and effectiveness of existing health services. Subsequently the Council's own health responsibilities widened significantly beyond its obligations in environmental inspection and protection: the Inspector's Department had an objective to enhance 'the climate for knowledgeable primary and preventive care'.¹³ In 1979, the MCC appointed the country's first Community Development Manager to head a new department that liaised with Maori and Pacific groups and co-ordinated and supported initiatives in community health, housing, employment and education.¹⁴

At an international level, the emergence of health promotion and the primary health care movement also focused on local and community-based action. In 1977, the World Health Organization (WHO) set a goal of 'Health for All by the year 2000' and the following year the Declaration of Alma Ata pledged to achieve this goal through primary health care; signatories agreed to involve greater community input in their health systems. In 1986, the Ottawa Charter for Health Promotion reaffirmed the goals set at Alma Ata with a conception of public health that focused on promoting health in its broadest sense, rather than just preventing disease:

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-

¹² Haigh and Dale, p.78.

¹³ 'Delivery of Health Services in Manukau City', Community Development Committee Minutes, 2 June 1983, p.16, ACAS.

¹⁴ Haigh and Dale, pp.78, 80.

being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment.¹⁵

One of the ways that the WHO translated this objective into action was through its Healthy Cities project. Also begun in 1986, this project focused on the environment as a key determinant of health and encouraged city authorities and planners to give health considerations a higher priority in urban planning and public policy. According to the WHO, creating a modern healthy city was no longer just about sanitation and clean water supplies, but ‘continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other ... in developing to their maximum potential’.¹⁶ Historian Virginia Berridge has explained that ‘rather than simply encouraging behaviour change’, health promotion focused on ‘capacity building for health’. Another feature of this public health movement was building strong local lobbies that bypassed national health authorities.¹⁷ Manukau City became New Zealand’s first ‘Healthy City’ in 1988.

By the 1980s, South Auckland was an area of growing community identity and cultural diversity, but also had considerable social and health problems associated with poverty. The MCC played an important role in supporting South Auckland communities as they developed their own hubs of community life. In this way, South Auckland provided opportunities for health professionals to work with communities to recognise health issues and design interventions to deal with them.

¹⁵ WHO, *An International Conference on Health Promotion*, Ottawa, Canada, 21 November 1986, URL: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>, accessed 15 January 2014.

¹⁶ WHO, *Health Promotion Glossary*, 2nd edition, 1998, p.13.

¹⁷ Virginia Berridge, *Marketing Health: Smoking and the Discourse of Public Health, 1945–2000*, Oxford, 2007, pp.17–18; Virginia Berridge, ‘Historical and policy approaches’, in Margaret Thorogood and Yolande Coombes, *Evaluating Health Promotion: Practice and Methods*, 3rd edition, Oxford, 2010, pp.19–20.

‘It was actually quite revolutionary’: The Whaiora Community Health Group

A group of Maori and Pacific homemakers from Otara, with little formal education, became the primary solution to diabetes in South Auckland in the 1980s. The daughters of one of these women, Lillian Hall, who died in 1995, have recalled the early days of this scheme and their mother’s involvement:

It was actually quite revolutionary for the time in the early 1980s you know... to go get people of those particular ethnicities and bring them together, train them... and have them go into the community and to visit people in their homes and talk about diet and exercise and testing their blood sugars in a very sort of down-to-earth way.... Mum looked after the Maori families and the Samoan lady the Samoan ... but then they all came together and they would all have fun and do these crazy things, exercise and things... Mum loved that work and the people loved her.... I don’t know if it was so much about the diabetes but just that someone came and cared about them I suppose.¹⁸

Despite their belief this scheme was ‘revolutionary’, as discussed above, there was an international movement towards such community-based approaches. How the scheme eventuated and operated in South Auckland then provides insights into the interplay of local factors, national health policy concerns and broader trends in health care innovations.

Lay community health workers had a long history. The WHO recognised Russian *feldshers* – lay people who provided medical assistance to the military in the seventeenth century as the earliest example, but it was in the mid-twentieth century that the role became firmly established. At this time, developing countries trained people from the communities they would serve to provide basic primary health care to dispersed rural populations.¹⁹ Lay community health workers also appeared in the developed world, notably in the United States as part of its ‘War on Poverty’ programmes in the late 1960s: targeting predominantly African-American urban ‘slum’ neighbourhoods, these programmes used local people to

¹⁸ Maureen Muller and Andrea Kire, Interviewed by C.E. Harper, 9 July 2012. Both sisters spoke interchangeably in this example.

¹⁹ Stephanie Stegman, ‘Taking Control Fifty Years of Diabetes in the American Southwest 1940-1990’, PhD dissertation, Arizona State University, 2010, p.167; Gill Walt, ‘Health Care in the Developing World, 1974 to the 1990s’, in Charles Webster, ed., *Caring for Health: History and Diversity*, United Kingdom, 2001, pp.260, 268–71.

identify health problems, provide health care and foster community advocacy and leadership.²⁰ With the primary health care movement, community health workers became more widespread but were often incorporated into existing health systems. For example, the United States Indian Health Service began to use community health representatives as a vehicle for cross-cultural communication in its hospitals.²¹

In her dissertation on diabetes in the American Southwest, Stephanie Stegman noted that ‘new manifestations’ of community health workers for specific diseases emerged in the 1980s; for diabetes, Indian Health Service model diabetes control programmes, which began in 1979, incorporated such workers into multidisciplinary clinics held on reservations and at medical centres. Although these programmes were part of the Federal government’s long-range plan to combat diabetes through translational research, they were organised in consultation with tribal health boards, which had their own goals for tribes to eventually direct and control their own health services.²²

In New Zealand, Maori also called for control over their own health care at this time. The self-determination movement of the 1970s focused on land rights and breaches to the Treaty of Waitangi, and as mentioned earlier, *te reo*: in the 1980s, health came to rival these issues as a key political issue for tribal development. Lisa Ferguson’s study of *marae*-based health initiatives of the Tainui iwi (tribe) showed that, as Maori health needs were incorporated into mainstream services in the post-World War Two era, Tainui people began to equate ‘health’ with doctors and nurses, sickness and disease. In the early 1980s, Tainui used lay community health workers to re-educate its people on Maori concepts of health, which were more akin to

²⁰ Stegman, pp.167–8.

²¹ *Ibid.*, p.169.

²² *Ibid.*, p.173.

the public health practice of health promotion.²³ Maori doctors played a key part in this shift at a national level. They emphasised how low socio-economic status and low self-esteem were products of colonisation, which contributed to the persistent health disparities between Maori and Pakeha.²⁴ However, they also wanted to move away from a focus on Maori problems towards Maori achievement: Maori-led health initiatives sought to rediscover Maori frameworks and methodologies and operated on common themes of Maori autonomy, control and values.²⁵

In March 1984, Maori health professionals, academics, community and tribal groups at the first national hui on Maori health, Hui Whakaoranga, defined a Maori health philosophy which, among other things, included a spiritual dimension that was absent from Western biomedical understandings of health. The participants advocated ‘by Maori for Maori’ health care, with specific recommendations for the health services to make resources available for marae clinics and community health programmes, where local Maori organisations or communities determined needs.²⁶ As will be seen, this context was highly important to the development of the Whaiora scheme in South Auckland.

Diabetes was a significant health issue in South Auckland that existing health care services could not adequately cope with. General practitioners would diagnose and treat people with diabetes, but many Maori and Pacific people remained undiagnosed and untreated until they ended up in the closest hospital, Middlemore, with late-stage complications. In 1982, diabetes recorded admissions to Middlemore Hospital cost \$1.38 million or 4.4 per cent of the total

²³ L.A. Ferguson, ‘Marae Based Health Initiatives within the Tainui Iwi from 1970–1995’, MA thesis, University of Auckland, 1997, pp.102–3.

²⁴ Derek Dow, *Safeguarding the Public Health: A History of the New Zealand Department of Public Health*, Wellington, 1995, p.233.

²⁵ Mason Durie, *Whaiora: Maori Health Development*, 2nd edition, Auckland, 1998, pp.52–62.

²⁶ Department of Health, *Hui Whakaoranga: Maori Health Planning Workshop*, 1984; Durie, p.54.

hospital budget.²⁷ The best informed estimates suggested there were 8200 people with diabetes in South Auckland, yet the only specialist outpatient services for the Auckland region were at the Auckland Hospital Diabetic Clinic, which a waiting list of up to six weeks.²⁸ The Clinic staff found that South Auckland patients often did not attend their appointments because of the cost of travel to the city, loss of work time and an absence of Maori and Pacific staff. Many Pacific migrants spoke limited English, were unfamiliar with the New Zealand health system, and had a fundamentally different understanding of diet and health to western nutritional science, which meant often they did not understand the purpose of their appointments and therapy.²⁹ There were no educational programmes or support groups and the Auckland Diabetic Society had no outreach services in the area.

Dr David Scott, who was the Medical Advisor for the Auckland Diabetic Society and an Auckland Hospital diabetes specialist, was greatly concerned with these service deficiencies for South Auckland patients. Scott had a distinguished career in endocrinology research and clinical care, but he also had personal qualities which made him empathetic to the particular needs in South Auckland.³⁰ Deeply religious, Scott had an affinity with the spiritual aspects of Maori and Pacific cultures and his colleagues have remembered him for his holistic

²⁷ G.J.S. Cooper and D.J. Scott, 'The cost of diabetes in South Auckland', *New Zealand Medical Journal* (NZMJ), 98, 773, 27 February 1985, p.113. As records might not cite diabetes as a primary cause of admission, the real figure was likely much higher.

²⁸ Planning Services and Works Committee, Auckland Hospital Board, 25 November 1985, Medical services – Care of diabetics, 1982–86, ZABV 4638 A1073 190/d 95/1/44 2, ANZA; Nesfield to Chief Executive, AHB, 9 May 1979, Medical services – Care of diabetics, 1955–82, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

²⁹ Scott to A.L. Honeyman, 7 December 1981, ZABV 4638 A1073 198/a 95/1/44 1, ANZA. These were common features of Pacific peoples' experience with the health system more generally at the time: see Deborah Dunsford, Julie Park, Judith Littleton, Ward Friessen, Phyllis Herda, Pat Neuwelt, Jennifer Hand, Philippa Blackmore, Sagaa Malua, Jessica Grant, Robin Kearns, Linda Bryder and Yvonne Underhill-Sem, *Better Lives: The Struggle for Health of Transnational Pacific Peoples in New Zealand, 1950–2000*, Auckland, 2011, pp.51–54. See also Losa M. Mota'ane, Soana Muimui-Heata and Barbara E. Guthrie, 'Tongan perceptions of diet and diabetes mellitus', *Journal of the New Zealand Dietetic Association*, 50, 2, October 1996, pp.52–56; and Lucy Christina Barnes, 'Cultural Perceptions of Diabetes Mellitus', Master of Science (Health Psychology) thesis, University of Auckland, 2000.

³⁰ Dr David Gray, 'Obituary: David John Scott', NZMJ, 120, 1252, 13 April 2007, URL: <http://www.nzma.org.nz/journal/120-1252/2507/>, accessed 20 March 2015.

conception of health, which they believed was unusual for a hospital consultant at this time.³¹

In 1980, Scott went on sabbatical to the United States where he visited community-based health clinics in underserved African-American communities and Indian Health Service diabetes programmes. This experience led him to consider utilising lay community health workers in South Auckland.³²

On his return from study leave, Scott supervised a young Maori registrar, Dr Papaarangi Reid, in a project where she trained five lay Maori women from Otara in nutrition, obesity and diabetes that demonstrated the feasibility of such an option.³³ Reid, who was deeply immersed in the black feminist movement of the time, stated that she undertook the project as she wanted to find a way to address the high rates of non-insulin-dependent diabetes (NIDDM) in urban Maori that did not ‘victim blame’. She argued most health professionals took this victim-blaming approach, whereas she saw New Zealand’s colonial history and ‘the racist and sexist system’ as key factors in the poor health status of Maori.³⁴ Reid believed the answer to diabetes was ‘not to put all of Otara on a diet’, but to provide good education, employment and move Maori out of the lower class.³⁵ In the meantime, she viewed lay health workers as a useful alternative: Reid described a recent initiative in which a Maori grandmother taught dental care to pregnant women at Middlemore Hospital. Reid suggested this initiative had proved that ‘health professionals aren’t needed’, and in any case, lay educators were more effective because they remained in the community once financing and medical interest waned.³⁶

³¹ Prof David Simmons, Interviewed by C.E. Harper, 5 April 2012; A/Prof Tim Kenealy, Interviewed by C.E. Harper, 22 August 2011.

³² Scott to J.A. Borrows, 2 February 1982, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

³³ Reid, ‘Elective Report’.

³⁴ Reid, ‘Elective Report’, pp.9, 4; Papaarangi Reid, ‘How to Get Out of Milking the Cows’, in Rosy Fenwicke, *In Practice: the Lives of New Zealand Women Doctors in the 21st Century*, Auckland, 2004, pp.76–87.

³⁵ Reid, ‘Elective Report’, p.5.

³⁶ Reid, ‘Elective Report’, p.6.

In 1982, Scott transferred from Auckland Hospital to Middlemore to set up a diabetes service for South Auckland. Scott proposed a radical departure from the traditional hospital clinic for South Auckland, which he argued ‘would be perpetuating our preoccupation with the end stage of the disease’.³⁷ Scott envisaged a multi-disciplinary team that included lay health workers, which would hold clinics at the hospital, primary care medical centres and a local school. School-based diabetes clinics already existed in New Zealand: Dr Doug Short of Whakatane Hospital ran one to serve the predominantly rural Maori community. However, Scott envisioned something larger, which he modelled after general community health schemes he had visited in the low socio-economic suburb of Wilmington, Delaware. Scott argued that ‘local people, with concern for their own health problems’ should direct ‘a community health clinic, shorn of control by traditional health agencies’.³⁸ He proposed that such a clinic would enable local people to ‘work out ways of tackling their local health problems’: schoolchildren would gain first-hand experience with diabetes patients and could recruit their parents for screening, and nutrition, cooking and exercise classes could be incorporated into the existing school health education programme.³⁹ Hillary College, a secondary school in Otara, had already indicated their interest in the scheme. Hospital administrators rejected the proposal because it was outside their responsibility and would cost too much.⁴⁰

Undeterred by this rejection, Scott and Reid approached members of the St Johns Catholic Church and Whaiora marae in Otara with a new lay worker initiative in mind. In the early 1970s, the Church fathers and Maori Catholic Society had seen a need for a marae to serve the

³⁷ Scott to J.A. Borrows.

³⁸ *Ibid.*

³⁹ *Ibid.*

⁴⁰ Medical Superintendent Middlemore Hospital to Chief Executive AHB, 30 March 1982, ZABV 4638 A1073 198/a 95/1/44 1, ANZA. Scott established a diabetes in pregnancy clinic at Middlemore Hospital and some mini clinics at medical centres in 1982, and an outpatient diabetes clinic and education centre at a house on Middlemore hospital grounds in 1986.

diverse ethnic groups of the parish and wider community.⁴¹ Built on parish land, largely through the community's voluntary labour, the Whaiora marae, a name that means 'in search of the better things in life', opened in 1977. Also at rooms on parish land, was an order of nuns who provided nursing and social services.⁴² Following Scott and Reid's approach, a prominent Whaiora member, June McIntosh, and nun and registered nurse Sister Michelle Carter, began to recruit local women as potential health workers.⁴³ The Maori, Tongan, Niuean, Samoan and Fijian recruits were fluent in their respective languages and well respected in the community; two had diabetes themselves.⁴⁴ In 1983, in their own time, Scott and another young Maori registrar, Dr Garth Cooper, trained the women, with support from a dietitian, diabetes nurse educator and the Auckland Diabetic Society. The training covered nutrition, diabetes screening and diagnosis, patient education and blood glucose testing, information on healthy lifestyles, budgeting and other common diseases.⁴⁵

In the first real test of their abilities, the lay health workers conducted two detection field days that exposed the seriousness of diabetes in Otara and stimulated community action. The workers screened 250 people at the Otara Town Centre and flea market and found twenty new cases of diabetes.⁴⁶ The results suggested that there were not only many undiagnosed people with diabetes in the community, but also that many people did not have a general practitioner, or any idea how to get one.⁴⁷ While the Health Department favoured using general practitioners to screen those at risk, this approach was not working in South Auckland at this

⁴¹ *St John's Otara Silver Jubilee, 1959–1984: Souvenir Booklet*, Manukau, 1984. The Department of Maori Affairs also provided funding, see Marae – Whaiora, 1971–1984, BBCZ 4410 16/a 5/4/2/1, ANZA.

⁴² J.A. Voyle and D. Simmons, 'Community development through partnership: promoting health in an urban indigenous community in New Zealand', *Social Science and Medicine*, 49, 8, October 1999, p.1040.

⁴³ They focused on women because they knew some Pacific men would not approve of men counselling women: see D. Simmons, J.A. Voyle, Elaine Rush and Murray Dear, 'The New Zealand experience in peer support interventions among people with diabetes', *Family Practice*, 27 (supplement 1), June 2010, p.i55.

⁴⁴ *Ibid.*; Health and Bylaws Committee Minutes 20 June 1984, Appendix J, ACAS.

⁴⁵ Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012;

⁴⁶ Garth Cooper, John Nesfield, S. Perera, Ellen Tito and David Scott, 'Lay community health workers detecting diabetes', *NZMJ*, 97, 760, 25 July 1984, p.502.

⁴⁷ *Ibid.*; Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012.

time.⁴⁸ At two hui at the Whaiora marae in January and May 1984, community leaders, Scott's team and local health officials discussed these results. The discussions led to the formation of a voluntary organisation, the Whaiora Community Health Group, to oversee a diabetes detection and education scheme.⁴⁹ The MCC played a key role in supporting the Group: it identified resources, contributed to operating costs, and formally recognised the lay workers with a training certificate and official award ceremony.⁵⁰

The Whaiora Community Health Group went on to establish a holistic, preventive and primary care service for diabetes in South Auckland. Recognising the centrality of families to Maori and Pacific people, the lay workers promoted the health of the whole family rather than just educating the patient. This health promotion approach also differed from mainstream diabetes education for family members, which focused on their roles as care-provider and support person. The workers adapted diabetes education to Maori and Pacific food preferences and practices. They went to community events and schools to screen for diabetes and talk about healthy living. People could come directly, without an appointment or fees, to their base at St John's 'white cottage' which hosted several other community groups and services including natural family planning, budgeting, parenting skills and a support group for the terminally ill.⁵¹ They also accepted referrals from health professionals to see patients and screen family members in their homes. Sister Michelle Carter acted as team leader for the lay workers and other religious Sisters helped with things like patient transport. The Group also initiated diabetes peer support groups in neighbouring suburbs.

⁴⁸ See Chapter Three.

⁴⁹ Health and Bylaws Committee Minutes, 20 June 1984, Appendix J, ACAS.

⁵⁰ Health and Bylaws Committee Minute No.1505, 20 June 1984, ACAS; Cooper had approached the Mayor, Barry Curtis, to arrange the qualification: Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012; Health and Bylaws Committee Minute No.2253, 21 August 1985, ACAS.

⁵¹ Employment Division – Community Employment Initiative Fund – St Johns Family Health Care Centre, 1984, AANK 947 W3580 657/ 52/206/1/89 1, Archives New Zealand, Wellington (ANZW).

Although the Group's focus was diabetes, its underlying philosophy was not disease-specific.

Sister Carter described in 1985 how the Group had a

holistic multifaceted approach [which] is important, if Polynesian people are to enable other Polynesian people to develop good health care in the community, and so enable people to come to: a state of complete spiritual, mental, family and physical unity, harmony and well-being. A Maori view of health.⁵²

Having its origins in the parish community gave the service religious underpinnings, but these were non-denominational and understood on cultural and social terms. Carter and her successor, diabetes nurse specialist, Angela Thornton, believed part of their role was empowering the workers to achieve their own personal goals and to develop their skills; they supported some workers to get their driver's licenses and others to attend various training courses.⁵³ Besides their community activities, the workers sometimes acted as translators for inpatients at Middlemore Hospital. The Group, however, felt its autonomy from the hospital was important: while there was a 'degree of co-operation with the existing health services. The community would retain overall control and direction.'⁵⁴ The Whaiora scheme thus had a community development orientation that reflected contemporary Maori views of health.

This context does not indicate a homogenous Maori view in the Otara community and the diabetes programme. Many Maori retained traditional tribal allegiances and while geographically Otara was Tainui territory, most of the initial Maori residents who moved

⁵² Submission from Sister Carter to Michael Bassett, reproduced in Health and Bylaws Committee Minute No.2253, 21 August 1985, ACAS. The Whaiora Community Health Group intended to begin with diabetes as the workers were already trained, and expand into other chronic diseases and health problems prevalent in the community as resources became available. This never eventuated as the workload with diabetes became so overwhelming, although additional asthma community health workers joined the team in 1989.

⁵³ Maureen Muller and Andrea Kire, Interviewed by C.E. Harper, 9 July 2012. The Group's annual reports include detailed sections on the development activities of individual workers. Thornton joined the group in 1986 and Kire became Centre-Co-ordinator after Thornton left in 1994. Kire and Muller went on to university and work in Maori language revitalisation strategy and analysis.

⁵⁴ 'Proposal for a Community Health Education Centre in Otara', Health and Bylaws Committee Meeting Minute No. 1505, 20 June 1984, Appendix J. In 1986 the Group came under the 'protection' of Middlemore, but staunchly defended their autonomy in the contract negotiations: see Whaiora Community Health Group, 'Promoting Diabetic Self Care in South Auckland', Community Development Committee Minute No.1449, 7 July 1988, Appendix H, ACAS.

there when the suburb was created in the 1950s had Nga Puhi roots. Over time Otara residents established a pan-tribal identity, 'Ngati Otara', which, according to a community development officer working there in the 1980s, underpinned a strong community view 'that we are all in this together', Maori, Pacific and Pakeha.⁵⁵ The growing proportion of Pacific residents, however, still sought to maintain separate cultural identities in the suburban environment. There were instances of violence and gang allegiances on ethnic lines amongst young people.⁵⁶ Such incidents attracted negative media scrutiny to Otara, but for the majority who lived there this was not the image they had of their community.⁵⁷ Nevertheless, Cooper recalled there were tensions with people involved in other Maori community development initiatives in the area over the inclusion of Pacific workers in the Whaiora scheme and its focus on diabetes rather than a strictly Maori political agenda.⁵⁸

Community ownership of the programme created bureaucratic challenges as well. In an interview for the purposes of this thesis, Cooper claimed that when they began some officials in the Health Department were sceptical and expected the workers, who 'could barely drive a typewriter', to show they were making a 'material impact' on diabetes in South Auckland.⁵⁹ Cooper was often the one who met with officials to raise funds, an experience he found was 'absolutely illuminating' of their attitudes. He believed he was perceived as 'just a dumb person from South Auckland' when he was not dressed up as a doctor.⁶⁰ Cooper suggested there was a 'clash of cultures' between Wellington officials and those working in the community. Ferguson documented a similar clash between the Tainui iwi and the Health

⁵⁵ James, p.185.

⁵⁶ A major example was the 'Otara Machete Murder' of Tongan youth David Fuko on 30 April 1988. This occurred in a brawl at the Town Centre after weeks of escalating tension between Samoan and Tongan teenagers: see 'Machete Case: Mounting Rivalry Led to Brutal Machete Killing', *New Zealand Herald*, 5 November 1988.

⁵⁷ James, p.185.

⁵⁸ Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012.

⁵⁹ Ibid.

⁶⁰ Ironic, considering, Cooper left Middlemore in 1986 on a Nuffield scholarship for Oxford University where he discovered the hormone amylin and developed pioneering new treatments for diabetes. He became a renowned biochemist and biotechnology entrepreneur and was named New Zealander of the year in 2003.

Department, as they established marae-based health centres and community health workers in the early 1980s. These struggles arose as the Department imposed what the workers saw as restrictive conditions, inappropriate job descriptions and funding arrangements.⁶¹ Reports from the time by Health Department officers who worked with community groups also indicate their difficulties with changing top-down practices amongst colleagues.⁶² Cooper additionally argued that the difficulties he faced with officials might have reflected the National government's (in office until July 1984) lack of political interest in the people of South Auckland, who were largely Labour party supporters.⁶³

There was a discernible shift in political support for the Whaiora Group under the fourth Labour government which came to power in July 1984. Labour officially recognised the obligations of government under the Treaty of Waitangi of 1840. It granted retrospective powers to the Waitangi Tribunal, set up in 1975, to investigate Crown breaches of the Treaty, and introduced policies for iwi development and biculturalism in the state sector. Whereas the previous government's Minister of Maori Affairs had stated 'there is no such thing as Maori health or Pakeha health; there is only people health', under Labour, Maori health became a priority area in the Health Department with increased support for Maori health initiatives.⁶⁴ Two experimental community development health programmes bolstered the number of Maori community health workers and put additional public health resources into 'at-risk' communities, which included South Auckland.⁶⁵ Although the Whaiora Group did not directly benefit from these resources, Labour members of parliament (MPs) expressed great

⁶¹ Ferguson, pp.69–70, 73.

⁶² Anne de Lacey, *Community Groups Working for Health: Issues and Experiences*, Department of Health Special Report Series No.68, Wellington, 1984.

⁶³ Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012.

⁶⁴ Department of Health, *Hui Whakaoranga*; Robin Gauld, *Revolving Doors: New Zealand's Health Reforms – the Continuing Saga*, Wellington, 2009, p.73.

⁶⁵ De Lacey, *Community Development in Health Part Two*; Michael Bassett to Ron Wood, 11 February 1985, Diseases – Diabetes, 1984–86, ABQU 632 W4452 667/ 131-20 (60257), ANZW.

interest in its work; the Prime Minister, David Lange (who had NIDDM himself), and the Minister of Finance, Roger Douglas, both of whom were MPs for South Auckland electorates, even joined the Group's incorporated Trust.⁶⁶ Furthermore, these political connections helped the Group achieve a contract with the Auckland Hospital Board (AHB), which enabled some of the workers to be paid from 1986. This was despite the Board's reluctance to consider that funding a voluntary community-based organisation was its responsibility.⁶⁷

As with the introduction of other community-based diabetes services, such as those discussed in Chapter Four, the Whaiora scheme provoked some resistance from general practitioners. Hospital administrators had in part rejected Scott's initial plan to set up community-based services as they feared general practitioners might perceive it as an encroachment on their territory.⁶⁸ Cooper has recalled that when the scheme began, he 'was really told off big time' by general practitioners who believed the lay worker scheme was 'Middlemore Hospital moving into their patch'.⁶⁹ Maureen Muller and Andrea Kire, daughters of the original Maori recruit, Lillian Hall, and themselves both community health workers with the Group from the mid-1980s recalled initial resistance from some local doctors. It is probable that general practitioners' resistance was not purely out of professional self-interest, as they may have inferred in the scheme a criticism of their own abilities to care for their patients and the community.⁷⁰

⁶⁶ The others were Roger Douglas, Colin Moyle and the Minister of Maori Affairs, Koro Wetere, Health and Bylaws Committee Minutes, 21 August 1985, Appendix H, ACAS.

⁶⁷ Michael Bassett to Carter, 23 July 1985, ZABV 4638 A1073 190/d 95/1/44 2, ANZA; Planning Services and Works Committee, 25 November 1985, ZABV 4638 A1073 190/d 95/1/44 2, ANZA.

⁶⁸ Medical Superintendent Middlemore Hospital to Chief Executive AHB, 30 March 1982, ZABV 4638 A1073 198/a 95/1/44 1, ANZA.

⁶⁹ Prof Garth Cooper, Interviewed by C.E. Harper, 22 February 2012.

⁷⁰ Certainly, the Chairman of the Royal New Zealand College of General Practitioners was angry with the denigration of general practitioners' care in media reports that quoted Dr David Scott on cuts to hospital diabetes services in 1989: see 'Diabetics Sour on Cuts', *Sunday Star*, 12 February 1989; and T.D.S. Seddon to D.J. Scott, 14 February, Medical Services – all institutions – care of diabetics, 1988–92, ZABV 4638 98/b 95/1/44 4, ANZA. This, however, is not in keeping with the recollections of a general practitioner who worked closely with Scott in a research capacity at this time: A/Prof Tim Kenealy, Interviewed by C.E. Harper, 22 August 2011.

Nevertheless, the workers eventually found themselves welcome intermediaries between general practitioners and patients. Andrea Kire remembered that those whom doctors called the ‘non-compliant’ patient usually did not understand their instructions.⁷¹ Kire and Muller pointed out that a big part of their work was about ‘teaching people to stand up for themselves’. They found the frightened and confused would often return to their doctor with the confidence and knowledge to ask, ‘What was my sera fructosomine [blood sugar measurement]?’ and in the process educate the doctor who did not know what that was. Kire says most doctors ‘eventually came to the party’ as they recognised that the workers had a greater chance of getting through to the patient.⁷² As general practitioners came to see better self-management in their patients, the workers received more and more referrals: in 1988, they made 7900 patient contacts, which placed considerable financial strain on the Group.⁷³

By the late 1980s, the Group saw itself as integral to diabetes management in South Auckland and sought a revision of its funding arrangements to reflect this. Fundraising took up a significant portion of the Group’s time, which was becoming more limited with the increased patient workloads. Health professionals from other parts of the country, and international guests, visited regularly to study the scheme as a model for not only diabetes, but also other chronic conditions such as asthma.⁷⁴ As its AHB contract came to an end in 1988 the Group Co-ordinator, Angela Thornton, launched a letter-writing campaign getting hundreds of general practitioners, dietitians, specialists, nurses and people with diabetes to request the

⁷¹ Andrea Kire, Interviewed by C.E. Harper, 9 July 2012.

⁷² Ibid.

⁷³ Simmons, Voyle, Rush and Dear, p.i55.

⁷⁴ Community Development Committee Minute No.602, 7 April 1988, ACAS; Whaiora Community Health Group Annual Report for 1 April 1988 to 31 March 1989, Diabetes and Asthma Centre South Auckland, ZABV 1973 897e, ANZA.

Board and Minister of Health, David Caygill, to fund adequate pay for the workers.⁷⁵ The workers themselves appeared on Maori and Pacific television programmes to raise community awareness.⁷⁶ The campaign worked: after a few months of the Group operating only three days per week and refusing to accept new referrals, Caygill authorised a \$25,000 government grant for it to restore services. By this time the Group had outgrown the rooms at St John's white cottage, and with asthma community health workers and nurses about to join the diabetes workers, they decided to move premises. With additional charitable funding grants and a Manukau Housing Corporation loan, the Group purchased a house in the neighbouring suburb of Papatoetoe where they operated as the South Auckland Diabetes and Asthma Centre (SADC) from 1989.⁷⁷

The political acceptability of the lay community health worker approach to diabetes in South Auckland was seen most clearly with changes to the health system at the end of the decade. Helen Clark replaced Caygill as Health Minister in 1989 and directed all remaining hospital boards to transform into area health boards. Diabetes benefited from a clearer direction under the Auckland Area Health Board (AAHB) to focus on community-based care and meeting special population needs, in particular those of Maori and Pacific communities. There was also a drive to integrate and co-ordinate public, private and non-profit service providers.⁷⁸ In February 1990, Clark approved the AAHB's request for a service development grant, which

⁷⁵ Angela Thornton, Interviewed by C.E. Harper, 7 February 2012.

⁷⁶ Letters are in ZABV 4638 A1073 535/a 95/1/44 3, ANZA; 'Interview with Nali Jackson', *Tagata Pasifika*, 9 July 1988, Television New Zealand Archives, Wellington (TVNZ); 'Whaiora Marae Diabetic Clinic', *Tagata Pasifika*, 4 June 1988, TVNZ.

⁷⁷ Whaiora Community Health Group Annual Report for 1 April 1988 to 31 March 1989. The cottage had already been known as the South Auckland Diabetes Centre for some time to avoid confusion with the Whitiara outpatient clinic at Middlemore, which Scott set up in 1986. Whitiara also had a strong focus on Maori and Pacific culture and a non-clinical atmosphere: David Scott, Sheryl French and George Rudy, 'Whitiara – a bridge to good health for South Auckland diabetics', *New Zealand Hospital*, November/December 1987, pp.19–21.

⁷⁸ Gauld, p.72.

earmarked \$294,300 for diabetes care in South Auckland with \$160,000 to go directly to the SADC. For the first time since 1983, all the workers would receive full pay for their time.⁷⁹

‘We were only touching the tip of the iceberg’: the South Auckland Diabetes Plan

Despite the initiatives of the 1980s, from the end of that decade the demographic and socio-economic situation in South Auckland suggested the area’s problems with diabetes were set to grow. The Labour government’s state sector restructuring and deregulation of the economy led to many redundancies, especially in the manufacturing industries. A 1987 review of the social impact of these policies in South Auckland revealed high rates of unemployment, a marked rise in people seeking help from voluntary agencies, a severe housing shortage and high cost of living.⁸⁰ The 1990–1993 National government’s social policies, which cut welfare benefits, introduced full market rents on state housing and user part charges for health care, led to further socio-economic deprivation. Additionally, South Auckland had the fastest population growth in the country, particularly of Maori, Pacific and now also Indian ethnicities, another group with a high prevalence of diabetes. Still a youthful population by national standards, South Auckland, as elsewhere, was ageing. Together, these factors indicated that more diabetes and its complications were on the horizon: as SADC community health worker Andrea Kire has reflected, ‘we were only touching the tip of the iceberg’ of people with diabetes.⁸¹ In the 1990s, more effort would go into determining the size of the diabetes problem in South Auckland and devising an integrated community response.

⁷⁹ South Auckland Diabetes Centre staff to David King, 21 February 1990, ZABV A1073 897e, ANZA.

⁸⁰ Patrick Hanly and Karen Goodall, *Regional Social Impact Review: South Auckland*, State Services Commission, March 1987, pp.28; 16–20; 6–12.

⁸¹ Phillipa Wilson and David Simmons, ‘The development of community oriented recommendations for diabetes care in south Auckland’, *NZMJ*, 107, 989, 9 November 1994, p.457. Angela Thornton and Andrea Kire both commented on the big increase in Indian people (many from Fiji) they began to see at the SADC in the 1990s: Angela Thornton, Interviewed by C.E. Harper, 7 February 2012; Andrea Kire, Interviewed by C.E. Harper, 9 July 2012.

Research surveys became an important driver of community efforts to control diabetes in South Auckland in the 1990s. As discussed in Chapter Five, the Diabetes Task Force, which was established in 1987, contributed a significant boost to funding for epidemiological research on diabetes. The first project to benefit from this support was the Workforce Diabetes Study, 1988–90, which investigated lifestyle risk factors and prevalence of diabetes amongst Pakeha, Maori and Pacific groups. South Auckland worksites featured prominently in the study in order to get large sample sizes of the latter two populations.⁸² This survey found that 76 per cent of Pacific participants with diabetes had poor glucose control, which the study's author, Dr Robert Scragg, argued meant that there was 'a major deficiency in the delivery of health care to this group'.⁸³ Scragg teamed up with Dr David Scott to devise a new study, the South Auckland Diabetes Survey, 1990–91, which involved interviews with 253 practice nurses and general practitioners and 555 patients. The results indicated that a large proportion of patients had potentially avoidable risk factors for diabetes complications: 80 per cent had poor foot care, one quarter had inadequately treated blood pressure and two thirds had poor glucose control. Between one and two thirds of patients (the figures varied for each ethnic groups) were categorised 'extremely obese'. These risk factors were more common in Maori and Pacific patients, of whom a sizeable majority wanted more education.⁸⁴ Scott felt, 'overwhelmed by the size of the problems' particularly 'the failure of the conventional medical systems to both capture the concern of the patients and provide effective care'.⁸⁵

⁸² MRC Grant Application, Community Based Diabetic Care in South Auckland, in Diabetes Task Force Minutes, 30 March 1990, YCBN 5805 2/c ANZA.

⁸³ Application for a Supplementary Grant, 22 February 1999, p.10, MRC Project Grants – Scragg/Baker, 1987-1991, YCBN 5815 91/b 88-14 ANZA.

⁸⁴ South Auckland Community Diabetes Planning Group, *Diabetes in South Auckland (Sugar Busters)*, November 1992, p.5; David Simmons, Lois Shaw, Tim Kenealy, David Scott and Robert Scragg, 'Ethnic differences in diabetes knowledge and education: the South Auckland Diabetes Survey', *NZMJ*, 107, 978, 25 May 1994, p.198. The patient in the survey attended one or a combination of general practice, Whitiara or the SADC.

⁸⁵ David Scott to Ingrid Ward, 14 January 1992, Health Education – Diabetes Video – Who's in Control? ABQU 632 W4452 1589/ 344-23-18 (72934), ANZW.

The South Auckland Diabetes Survey team called for better integration of all diabetes education with primary care and the ‘full involvement of the communities concerned’ in evaluating and planning services: the first step towards these objectives was the South Auckland Diabetes Plan.⁸⁶ A core working committee of representatives from the MCC, Middlemore, general practice, Manukau Polytechnic and Maori and Pacific groups spent five months of community consultation and, with the technical advice of diabetes health professionals, came up with this district-wide plan, which it distributed to all general practitioners and diabetes care providers in the region.⁸⁷ Launched in November 1992, the Plan’s stated aim was ‘to prevent the growth in the number of diabetic patients and to reduce the current costs of hospital care’.⁸⁸ To do this, its sixty-eight recommendations addressed the demographic and socio-economic environment and the co-ordination of diabetes services by emphasising a ‘community empowerment approach’. This entailed reducing the personal costs of diabetes management, increasing patient, family and community knowledge, and providing pathways for them to influence local diabetes services. The Plan drew on principles established with the 1989 St Vincent’s Declaration, a European-wide framework which set population targets for secondary prevention of complications and standards of care, but in South Auckland these were to be integrated with primary prevention.⁸⁹

The South Auckland Diabetes Plan aligned with the international new public health movement. The WHO’s Healthy Cities project encouraged local governments’ to engage in ‘intersectorial collaboration’ with other agencies and to incorporate views from all groups within the community, at the grassroots level, to target local problems with innovative solutions. This approach was clearly apparent with the community input in the diabetes

⁸⁶ Simmons et al., ‘Ethnic differences in diabetes knowledge’, p.200.

⁸⁷ Wilson and Simmons, p.457.

⁸⁸ South Auckland Community Diabetes Planning Group, p.16.

⁸⁹ Wilson and Simmons, p.459.

planning process in South Auckland. Moreover, Council officers involved with the Healthy City programme sat on the planning committee of the Diabetes Plan and local body politicians played a prominent role in publicising it.⁹⁰ The South Auckland Diabetes Project (SADP), which was set up to work towards the Plan's recommendations, made explicit connections in its research papers between its aims and the ethos of the 1986 Ottawa Charter for Health Promotion.

The SADP's medical director, Dr David Simmons, had joined Scott's team at Middlemore in 1989. An enthusiastic young registrar from England with a background in epidemiological research, Simmons saw parallels in South Auckland to the predominantly South Asian community of Coventry: he had been involved in the Coventry Diabetes Study which had linked an investigation of diabetes prevalence rates with a public education campaign and establishment of an Asian diabetes support group.⁹¹ This experience was formative in Simmons' ideas about his purpose as a scientist; one of the major lessons he learned was that scientific research for its own sake was exploitation when something was not given back to the community.⁹² During the community consultation for the South Auckland Diabetes Plan, Simmons devised a similar study to the one in Coventry with guidance from Middlemore's Maori and Pacific cultural advisors, Betty Hunapo and Christina Tapu, who disseminated proposals through their local networks. The SADP, according to Simmons, represented a fundamentally new approach to medical research whereby partnerships with a range of ethnic and social groups and care providers created a 'shifting experiment' in the community.⁹³ The

⁹⁰ A/Prof Tim Kenealy, Interviewed by C.E. Harper, 22 August 2011; South Auckland Community Diabetes Planning Group.

⁹¹ D. Simmons, 'Diabetes self-help facilitated by local diabetes research: the Coventry Asian Diabetes Support Group', *Diabetic Medicine*, 9, 9, November 1992, pp.866–9.

⁹² Prof. David Simmons, Interviewed by C.E. Harper, 5 April 2012.

⁹³ SADP Three Year Report August 1994, p.2, Research project - Simmons - Diabetes and its tissue damage in South Auckland: assessment of prevalence and an innovative community intervention strategy, 1992–94, YCBN 5815 A1543 269/a 92/610, ANZA.

underlying goal was to establish baseline data about diabetes in South Auckland while piloting primary prevention initiatives through community development.⁹⁴

The SADP's first task was to establish the prevalence of diabetes in South Auckland. Over 1992–95 the SADP conducted a house to house survey of all households in inner urban South Auckland (the suburbs of Mangere, Otara, Papatoetoe and Otahuhu) to find the prevalence rates of known (already diagnosed) diabetes and those willing to participate in further interventions.⁹⁵ The age-adjusted results were that 1.9 per cent of Europeans, 5.2 per cent of Maori, 4 per cent of Pacific and 4.3 per cent of 'other' ethnic groups (mainly South Asians) had diabetes; however, prevalence rates reached as high as 15 per cent in Maori and Pacific people over fifty years of age.⁹⁶ Validated against census and general practitioner records, the survey contributed towards a district-wide diabetes audit system and a Diabetes Care Support Service was set up to assist general practitioners with patient recall and clinical advice. This data and service development formed the basis of much of the integrated diabetes management policy rolled out nationally at the end of the 1990s and, as of 2006, South Auckland remained the only area in New Zealand with such a comprehensive epidemiological picture of diabetes.⁹⁷

⁹⁴ D. Simmons, T. Weblemoe, J. Voyle, A Prichard, L. Leakehe and B. Gatland, 'Personal barriers to diabetes care: lessons from a multi-ethnic community in New Zealand' *Diabetic Medicine*, 15, 11, 1998, p.958.

⁹⁵ The survey did not screen for new cases of diabetes as the research team considered this unethical without providing ongoing care, which considering the inadequacy of existing services to cope with demand, was implausible. For more on screening debates in the 1990s, see Chapter Six and Wellington School of Medicine, "*Hui Whakamaarama*" *Report of a Consensus Hui Concerning Screening Amongst Maori*, Wellington, June 1993.

⁹⁶ David Simmons, Trish Harry and Barbara Gatland, 'Prevalence of known diabetes in different ethnic groups in inner urban South Auckland', *NZMJ*, 112, 1094, 27 August 1999, pp.316–9.

⁹⁷ David Simmons, Tim Kenealy and David J. Scott, 'Implementing the South Auckland Diabetes Plan', *NZMJ*, 113, 1116, 25 August 2000, p.364; Grace Joshy and David Simmons, 'Epidemiology of diabetes in New Zealand: revisit to a changing landscape', *NZMJ*, 119, 1235, 2 June 2006, URL: <http://www.nzma.org.nz/journal/119-1235/2004/>, accessed 6 January 2010.

The SADP aimed to empower the South Auckland community to overcome the conditions that exacerbated diabetes and its complications. As a starting point the SADP wanted to show the people of South Auckland it had a long-term commitment to their well-being. Under Simmons' influence, its household survey was not just about gathering information; it was also an exercise in raising community awareness and providing South Auckland people with new skills and opportunities. The SADP organised local long-standing unemployed people to undertake the door-knocking and data collection after they had attended a six-month diabetes fieldwork course at the Manukau Polytechnic. The trainees learned about diabetes, nutrition, first aid, communication skills and computing with the intention that following the survey they could become community diabetes educators, or at least have better employment prospects. Following on from the fieldwork course, in 1992, the Manukau Polytechnic instituted the first lay diabetes community educator qualification in the country. The qualification, designed with input from community representatives, aimed not only to address diabetes; by developing participants' work skills and supporting them into jobs or further education on completion, the course was a way to address the local unemployment problem and lack of Maori and Pacific health professionals. While the cultural acceptability of lay community health workers trained in diabetes in South Auckland was well-established, their effectiveness had not been scientifically evaluated and the SAPD saw the course as an opportunity to do so. The SADP evaluation demonstrated, as had been suspected with the original workers in the 1980s, that lay people could be effective educators in primary prevention and group settings.⁹⁸

The commitment to expanding employment opportunities in South Auckland was a distinctive element of the SADP's approach; however, its primary prevention programme was part of a

⁹⁸ Pamela B. Tregonning, David Simmons and Carole Fleming, 'A community diabetes educator course for the unemployed in South Auckland, New Zealand', *The Diabetes Educator*, 27, 1, January/February 2001, pp.94–100.

larger move towards community-based interventions in diabetes for high-risk populations. Stegman's work on diabetes in the American Southwest documented the emergence of this trend in the late 1980s with examples of both indigenous and Hispanic community coalitions with research projects or public health programmes.⁹⁹ Simmons' attended the Third Diabetes and Indigenous Peoples Conference in Winnipeg in 1995 where speakers presented on several projects underway in North America and Australia.¹⁰⁰ Over the 1990s, the SADP piloted and evaluated a number of interventions such as targeted videos for Maori, Pacific and Pakeha groups, nutrition and exercise classes, and support groups held at marae and in Pacific Island churches. In the Pacific Island church programme, the SADP worked with churches for different denominational and Island congregations who chose and prioritised the activities they wanted. The idea was that the community ultimately owned and would take over running the programmes. Some churches began to have members lead exercise classes, serve healthier food at events, negotiate with local gyms for reduced fees and even influenced their Church hierarchy outside of New Zealand.¹⁰¹

Thus, the South Auckland Diabetes Plan and SADP attempted to extend the schemes of the 1980s to empower communities to prevent diabetes and its complications, explicitly connecting this objective to new public health principles. The SADP's research, however, found that many people with diabetes believed that self-care had more disadvantages than benefits.¹⁰² This reflected perceptions that they had to give up things they enjoyed and the problem of motivating action in an asymptomatic stage of the disorder: as one research paper put it, 'Socio-economically disadvantaged people had other more immediate priorities than

⁹⁹ Stegman, pp.164–204.

¹⁰⁰ D. Simmons, J. Voyle, B. Swinburn and K. O'Dea, 'Community-based approaches for the primary prevention of non-insulin-dependent diabetes mellitus', *Diabetic Medicine*, 14, 7, July 1997, pp.519–26.

¹⁰¹ South Auckland Diabetes Project Four Year Report, August 1995, p.5; South Auckland Diabetes Project Six Year Report, August 1997, YCBN 5815 A1543 269/a 92/610, ANZA.

¹⁰² Simmons et al., 'Personal barriers to diabetes care', pp.958–64.

worrying about possible complications from their diabetes in the future'.¹⁰³ Could community empowerment survive the challenge central government's social and economic policies placed on the people of South Auckland in the 1990s?

Cutting costs or empowering communities?

South Auckland's community empowerment approach to diabetes control coincided with governments that desired to cut the costs of the welfare state and encourage personal responsibility for health care. The contested discourses of the residual welfare state and community development had real implications for the ongoing challenge of 'dealing to diabetes' in South Auckland.

Recent academic scholarship on community development in the Western world has highlighted the ambiguous nature of the concept that has made it vulnerable to appropriation for diverse political purposes.¹⁰⁴ Most scholars note that when community development emerged as a professional practice in the 1960s it was conceived of as an emancipatory and collective response to structural inequalities. Leftist community development practitioners viewed their work as a way to operate outside what they believed was a paternalist, oppressive welfare state that advantaged capitalist, patriarchal and colonial interests. However, some also pointed out that community development could embody functions that were more conservative in its congruence with a self-help ethic, or as a technique for social control.¹⁰⁵

¹⁰³ Simmons, Voyle, Rush and Dear, p.i59.

¹⁰⁴ Gary Craig, 'Introduction: Community Development in the United Kingdom', in Gary Craig, Marjorie Mayo, Keith Popple, Mae Shaw and Marilyn Taylor, eds, *The Community Development Reader: History, Themes, and Issues*, Bristol, 2011, pp.3–22; Mae Shaw, 'Community development and the politics of community', in Craig et al., pp.301–8.

¹⁰⁵ Marilyn Taylor and Keith Popple, 'In and Against the State: The 1950s to the Late 1970s', in Craig et al., pp.25–31.

With their previous critiques of the welfare state as a form of social control, by the 1980s and 1990s, many community development practitioners found themselves uncomfortable defenders of the welfare state against neoliberal economic reforms and reduced funding for social services.¹⁰⁶ Government political rhetoric espoused the superiority of the market and voluntary sector as more responsive and innovative in meeting community needs. This appeared to reduce the power of the state in favour of its citizens, but the changes could also constitute an abdication of the state's responsibility for social problems. Mae Shaw and Gary Craig have argued that the state increasingly turned to 'those already most disadvantaged communities to take on significant active citizenship roles in service delivery while rights to publicly funded services' were eroded.¹⁰⁷ In this context, 'community empowerment' became a method to decrease an alleged social scourge of welfare dependency and was often conflated with an individualistic notion of 'consumer' choice.

In New Zealand, this neoliberal ethos underpinned the National government's understanding of health inequalities and its reforms of the health sector in the early 1990s. The government perceived that health outcomes were largely linked to an individual's lifestyle choices. How certain 'choice' related illnesses, like NIDDM, were closely associated with poverty and ethnicity could be explained as the results of a non-responsive state monopoly on health and social services.¹⁰⁸ The health reforms split government's purchasing and provider functions, introduced competitive tendering and promoted an increased role for community and private providers. As social policy historian Michael Belgrave pointed out, 'The reforms aimed to provide financial incentives for healthy behaviour' through user part charges, the promotion of private insurance and reduced state funding. The government also argued that, 'Creating

¹⁰⁶ Mae Shaw and Marjorie Mayo, 'In and Against the Market: Mid- to Late 1970s to Early 1990s', in Craig, et al., p.112; Ewen Derrick, *Community Development and Social Change*, Auckland, 1993, pp.9–20.

¹⁰⁷ Mae Shaw and Gary Craig, 'Between the State and the Market: the Mid 1990s to the 2000s', in Craig, et al., p.197.

¹⁰⁸ Michael Belgrave, 'A Historical Perspective on the Politics of Health Care', in Dew and Matheson, p.78.

quasi-markets in health care ... turning patients into clients, together with the development of Maori and Pacific health providers', would improve service quality and the participation of disadvantaged groups.¹⁰⁹ The prevailing belief was that these measures would create services that were more efficient – at less cost to the state – while giving consumers' choice in how to meet their specific needs.

Much of the discourse that accompanied the health reforms appeared to align with that of community development approaches to public health. To recap from Chapter Six, the move away from universal services and recognition of differentiated health needs saw the government stress the importance of finding local solutions to local problems. As such, government rhetoric espoused that community groups could reach 'at-risk' populations and provide the supportive environment for behavioural change better than government-imposed services.¹¹⁰ These apparent similarities with the goals of community development, however, elide divergent philosophical positions: community development methodology aimed at improving public health through enabling people to participate fully in society as citizens, not as the self-interested consumer of neoliberal discourse. The process-focussed notion of community empowerment also did not fit easily with government contracts which prescribed quantitative measures of effectiveness and accountability.¹¹¹ Moreover, funding of community groups was often inadequate to meet the increased workloads they faced due to government cost-cutting measures.¹¹²

¹⁰⁹ Ibid., p.78.

¹¹⁰ Katherine, O'Regan, 'A challenge by the Honourable Katherine O'Regan to DNZ', (transcript of speech to conference), *Breakthrough*, 8, 2, Winter 1994, p.10.

¹¹¹ For a discussion of these issues in the United Kingdom, see Shaw and Craig, p.193.

¹¹² Margaret McClure, *A Civilised Community: A History of Social Security in New Zealand, 1898–1998*, Auckland, 1998, pp.409–12.

The South Auckland approach to dealing with diabetes reflected the uncomfortable juxtaposition of the goals of cutting costs and community empowerment. Those who advocated community-initiated solutions to diabetes in South Auckland believed these would improve health outcomes, particularly for Maori and Pacific people. Yet they often adopted the discourses of cost-cutting and moral responsibility. Dr David Simmons estimated the SADC could reduce the cost of diabetes to the nation's health bill by at least 20 per cent. The Health Department's public relations journal, *Health*, quoted Simmons:

Many diabetics end up out of work. They may have a lot of kids. That means you get a huge number of people dependent on the state as a result of diabetes.... We are there as facilitators, but they are the ones who are going to have to make the decisions – and coax their communities towards a safer path.¹¹³

While saving the state money on welfare was not Simmons' primary interest in community development interventions for diabetes, that the article emphasised this angle reflects the National government's intentions to force greater individual and community responsibility through its welfare and health reforms.

Another sign of these ambiguities was in the SADC's experiences in the 1990s reform environment. With more restrictive contracts and audit requirements, the SADC lost a large amount of its autonomy. Since losing its connection to the Whaiora marae when it moved premises in 1989, it also became more focused on service delivery than community development.¹¹⁴ Even more troublesome for the workers, the reforms caused a lot of disruption and uncertainty about further funding. The SADC never received the final instalment of its Service Development Grant awarded in 1990. Its 1992 annual report recorded how

Various Ministers of Health, Director Generals of Health, Hospital Board Executives and Area Health Board Directors have verbally stated that SADC saves a great deal of

¹¹³ Dr David Simmons, quoted in Ashton, 'Dealing to diabetes', p.16.

¹¹⁴ Andrea Kire, Interviewed by C.E. Harper, 9 July 2012.

money by maintaining people's lives in the community and avoiding hospitalisation, sickness benefit application and disablement. How long do staff of the South Auckland Community Health Group Inc have to continually expend time and energy in seeking funds when their training and expertise is needed to educate and support diabetic people toward fulfilled lives?¹¹⁵

Staff worked long hours in excess of what they were paid for, and with the South Auckland research suggesting Pacific diabetes rates would double over the next decade, the SADC viewed its work as an essential service to which the government needed to pay more than just lip service. In the mid-1990s the SADC closed, its diabetes nurse specialists absorbed into the hospital system and lay health workers into primary care.¹¹⁶

Inadequate funding and the health reforms also proved major obstacles to implementing the South Auckland Diabetes Plan. The Plan was launched just prior to the reforms, which replaced most hospital management staff and brought in new arrangements for funding general practitioners and health promotion. However, the new Ministry of Health and Northern Regional Health Authority, North Health, recommended continued support for the Plan's implementation.¹¹⁷ Drs David Scott, David Simmons and Tim Kenealy, who had all contributed to the formation of the Plan, reviewed its progress in 2000. They found that underfunding of clinical services, employing no extra dietetic, education and medical staff and the personal costs of self-management (which increased under the new health system) had seriously hampered its implementation. They argued 'the big fail' was in co-ordination of services which they attributed to 'the competitive purchasing model' and lack of protected staff time for such activities.¹¹⁸ Furthermore, there had been no co-ordination of primary prevention activities. The SADP received only ad hoc funding from the Health Research Council, pharmaceutical companies, charitable agencies and the Regional Health Authority

¹¹⁵ South Auckland Community Health Group Annual Report for the year ended 31 March 1992, p.4, Primary Health Care – Diabetes, 1989–92, ABQU 632 W4452 1841/ 358-60-4 (74885), ANZW.

¹¹⁶ Simmons, Voyle, Rush and Dear, p.i55.

¹¹⁷ Simmons, Kenealy and Scott, p.364.

¹¹⁸ Ibid, pp.364–5.

for its studies and interventions.¹¹⁹ Scott, Simmons and Kenealy suggested it was only due to the lobbying of ‘a number of enthusiastic individuals’ that just over half the recommendations were implemented. Referring to data which demonstrated that South Auckland patients’ blood glucose and blood pressure levels worsened between 1991 and 1997, the doctors considered the implementation of the remainder of the plan a matter of urgency.¹²⁰

Empowering Maori and Pacific communities also faced difficulties from underfunding. The SADP believed its long-term commitment to Maori and Pacific communities was the most important factor in establishing the trust necessary for success, but programmes often had to rely on short-term funding. A partnership for a diabetes health programme with the Whaiora marae in 1994 struggled with Maori distrust and suspicion. The SADP researchers attributed this to the history of colonisation in general, and government funding bodies which subverted the community’s self-determination. For example, marae members wanted paid employment opportunities as a tangible benefit of the programme, yet North Health did not even reply to a funding application for a marae-administered health worker. This was despite North Health funding the SADP researchers.¹²¹ The Manukau Polytechnic course for Maori and Pacific diabetes educators was reasonably successful: thirty individuals graduated and most gained employment in the health sector. However, North Health withdrew funding for the course in the late 1990s and the South Auckland Diabetes Plan’s recommendation of funding six extra community educator positions never eventuated.¹²²

Although by the late 1990s some of the SADP’s interventions (such as the church programme in the Samoan community) achieved positive results, others struggled against the continued

¹¹⁹ See annual reports in YCBN 5815 A1543 269/a 92/610, ANZA.

¹²⁰ Simmons, Kenealy, and Scott, p.365.

¹²¹ Voyle and Simmons, ‘Community development through partnership’ pp.1043–44.

¹²² Simmons, Kenealy and Scott, pp.364–65.

destructiveness of diabetes in South Auckland. Facilitators of peer support group meetings reported how these gave them insight ‘into the day-to-day reality’ of the disempowerment of people with diabetes. The SADP’s 1996 annual report noted that ‘we never cease to be amazed at the many fallacies which need to be corrected and the huge gaps in people’s information’ and ‘when we visit homes and repeatedly learned first-hand of disproportionate numbers of people who had recently died or are too sick to leave their homes’.¹²³ It appears the challenges of the mid-1980s remained: Maureen Muller has recalled one of her strongest memories of her mother’s work as an original Whaiora community health worker, was when she went with her to visit a man only to find him alone, dead in his home. Muller sat in shock as she watched her mother clean his body.¹²⁴

Conclusion

South Auckland’s community-driven solutions to deal with its major public health problem of diabetes developed in concert with central government efforts to contain or cut public expenditure in the 1980s and 1990s. The neoliberal paradigm of this era bolstered conceptions of health problems like NIDDM as the product of an individual’s poor lifestyle choices. However, this paradigm could also support the argument that the higher propensity for diabetes and its complications in the Maori and Pacific population were evidence of the state’s failure to respond to divergent consumer needs. From this perspective, marginalised communities were reconceptualised as consumer groups who could influence the development of services and policies, at a local level, in beneficial ways. Empowering Maori and Pacific communities with the knowledge and self-esteem to avoid or manage diabetes, in culturally acceptable ways, would theoretically reduce dependency on public resources.

¹²³ SADP Five Year Report, August 1996, pp.9–10, YCBN 5815 A1543 269/a 92/610, ANZA.

¹²⁴ Maureen Muller, Interviewed by C.E. Harper, 9 July 2012.

At a superficial level, such discourse aligned with the concerns of some health professionals, the local council and Maori and Pacific communities about a mono-cultural and inaccessible health system which could not deal to diabetes in South Auckland. The solutions to this problem, from the Whaiora Community Health Group to the SADP, took a community development orientation to prevent diabetes and its complications. The coherence of the South Auckland approach with government policy directions is evident in its influence on diabetes public health policy at a national level.¹²⁵ Yet, one of the distinctive features of South Auckland's framing of its disproportionate burden of diabetes was that this was a structural problem of poverty and not just the lifestyles of its 'high risk' ethnicities. Thus, while many individuals with, or at risk of developing diabetes, were empowered through the new approaches in South Auckland in the 1980s and 1990s, this must be contextualised against the many more who continued to face socio-economic hardship worsened by the government's cost-cutting agenda.

¹²⁵ The Whaiora scheme was used in the Department of Health's 1988 *Diabetes Mellitus: A Model for Health Maintenance* and the SADP in the Ministry of Health's 1997 *Strategies for the Prevention and Control of Diabetes* as culturally appropriate and promising community approaches to diabetes.

CONCLUSION

Empowering people with, or at risk of diabetes ‘towards self-sufficiency’ was a dominant theme in the history of diabetes in the twentieth century. The international historiography on diabetes, however, has often focused on control: technological progress in the biological control of the disorder, professional control of patient behaviour, disciplinary control of professional behaviour, policy control of the costs of diabetes and, ultimately, a lack of control as diabetes persists as, arguably, the most important public health issue of contemporary times. Alternatively, there is a history of expanding attempts to manage risks and align competing perspectives on the importance of those risks. This history of diabetes in New Zealand has at times built on, and at other times, questioned these themes. In the process, it has highlighted the attempts to enable people with, or at risk of diabetes to take responsibility for their health and well-being. This goal had considerable social and political value in mid to late twentieth-century New Zealand because it could represent diverse notions of health citizenship and ideologies of public health.

Self-sufficiency was a term that emerged from the modern patient education movement, which began in the 1970s, and continues to be a central facet of diabetes management today. Initially, new forms of organised diabetes education in the community aimed to reduce costly hospitalisations and complications; over time, the focus shifted towards integrating education with treatment, within the health services more generally, but with the same objective. By examining the role of consumer groups in this movement to empower people with diabetes and their primary care providers to take more active roles in diabetes management, this thesis has challenged both perspectives that view diabetes education as a form of social control, and those that suggest new service configurations reflected a reductive view of ‘patient-as-

biosign'. It also has shown that, in the New Zealand context, the rise of self-sufficiency was associated with debates between diabetes nurses and dietitians over professional identity and status, and their promotion of a model of care that was distinct from traditional medical approaches.

More broadly, the concept of self-sufficiency appeared earlier in the twentieth century, in the self-help philosophy of the diabetes consumer movement. In New Zealand, these societies were not simply forerunners to medical professionals' later engagement with self-sufficiency, or controlled by paternalistic doctors. Societies of 'diabetics' and their families emerged and grew in response to concerns about access to insulin, Social Security provisions and public health during the period of the classic welfare state. However, these societies also aimed to reshape perceptions that they were 'bludgers' on the public purse and strategically presented people with diabetes as responsible, self-reliant citizens. For children, diabetic societies aimed to ease the social challenges of their condition through supporting them, and their parents, to 'live a normal life despite diabetes'.¹ In line with other recent histories of voluntary welfare in New Zealand, this thesis has argued for the importance of values of self-help and a shared sense of civic responsibility in diabetic societies' relationships with government during this period.

These consumer groups' activities highlight the need to be wary of omnipresent state and medical authority in the mid-twentieth century. For example, the first blood-based detection drive in New Zealand, in 1965, was the result of John Nesfield, a lay member of the Auckland Diabetic Society, attending an overseas conference and obtaining the latest testing technology, despite it not having regulatory clearance. He organised media publicity and technicians to

¹ This was the slogan for the 1971 World Health Day commemorating the fiftieth anniversary of insulin.

conduct over 600 tests on an enthusiastic general public at the Auckland Easter Show. While an aggrieved local medical officer of health despaired ‘what is the future now for preventive surveys if voluntary bodies are to invade the field?’, the Director-General of Health simply asked the Society for more information about the procedure and results.² After initial enthusiasm buoyed by overseas findings, technological developments and optimism about early detection, mass screening went out of favour with most health officials and experts over the 1970s to 1990s as they believed evidence of benefit was outweighed by lost opportunity costs and potential for harm. Nevertheless, voluntary societies remained enthusiastic about detection campaigns and lay involvement was a feature of community screening programmes and proposals, even though health professionals repeatedly voiced their concern.

By the late twentieth century, self-sufficiency had taken on new meaning in the relationship between the lay diabetes movement and the state. Entering the 1990s, the close to bankrupt Diabetes New Zealand (DNZ) received government funding, for the first time, as part of what Margaret Tennant described as ‘the contract crunch’.³ The government provided this funding, ironically, for the organisation to meet ‘the object of self-sufficiency’.⁴ Encouraging self-sufficiency was a key objective of neoliberal-inspired social policy and developing the community sector to take more responsibility for health and welfare provision was an overarching aim of the National government at this time. Associate Health Minister Katherine O’Regan viewed DNZ’s work as useful to meeting government aims of reducing hospital costs, promoting consumer choice and being more responsive to needs at the community level. Thus, a contract for DNZ to sell blood glucose testing strips was an alignment of the

² E.P. Simpson to C.N. Derek Taylor, 15 December 1964, Diseases – Diabetic Survey, 1920–71, ADBZ 16163 H1 1237/ 131/20/6 (45365), Archives New Zealand, Wellington (ANZW).

³ Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840–2005*, Wellington, 2007, p.200.

⁴ Steve Anderson, General Manager, Contract Management Group, to Simon Upton, 30 September 1991, Primary Health Care – Diabetes, 1991, ABQU 632 W4452 1840 358-60-4 (70687) ANZW.

objectives of patient self-sufficiency, the voluntary organisation's ethos of self-sufficiency and the government's underlying political ideology.

Self-sufficiency could also represent the epidemiologically informed lifestyle approach to public health. Building on the work of Aaron Mauck and Stephanie Stegman in the United States, this thesis has demonstrated the importance of new epidemiological techniques in the framing of diabetes as a public health problem, and strategies for intervention. As high rates of diabetes mortality and morbidity were 'discovered' in Maori in the 1960s, the assumption was that Maori were failing to seek diagnosis early enough; medical officers of health undertook detection drives of their whole districts, but often with a special focus on revealing 'hidden diabetics' in the Maori population. Nevertheless, mostly understood as a hereditary disease that was more common in the elderly and amongst women who had large babies, family history, age and obstetrical history were the primary risk categories. By the 1980s the results of population-based studies such as Ian Prior's, which confirmed a gradient of diabetes prevalence between Maori and Pacific groups living in different stages of 'Westernisation', focused public health attention on modifiable lifestyle factors associated with obesity. To the researchers, a proposed genetic predisposition of the 'Polynesian' to diabetes was of less importance than community involvement in healthy lifestyle education, from a young age, an idea which gained increasing currency over the last two decades of the twentieth century.

The increasing identification of Maori and Pacific people as 'at-risk' groups for diabetes came at a time another form of self-sufficiency was taking hold, Maori self-determination, which influenced new approaches to diabetes in New Zealand. In the 1980s, Maori challenged both the efficacy and the appropriateness of mainstream health services to meet Maori health needs in the face of persistent inequalities they saw as rooted in the history of colonisation and

breaches to the Treaty of Waitangi. To many Maori, the contract crunch in the 1990s appeared to be an opportunity for increasing Maori participation and autonomy in health. The call for ‘by Maori for Maori’ services was seen in the development of marae-based approaches to diabetes and the formation of a separate advocacy group, Te Roopu Mate Huka in 1994. Pacific people also advocated ‘by Pacific for Pacific’ approaches to diabetes at this time.

The emphasis on diabetes as a lifestyle and Maori and Pacific problem coincided with the clearer demarcation of two distinct types of the disorder, which had important consequences for social attitudes and advocacy. In the 1980s, professional and lay diabetes organisations attempted single-issue advocacy to give diabetes a higher public and political profile amidst an array of competing voluntary health organisations and concerns about restricted government spending. The outcomes of this were largely dependent on whether they aligned with other government health policy objectives, which by the end of the decade included a public health goal to reduce nutrition-related disorders. As part of this, the Minister of Health required Area Health Boards to plan interventions for those ‘at-risk’ of Type 2. Over the next decade, the government, DNZ and media focused increasingly on the rising rates of Type 2. Subsequently, public perception that the person with diabetes was a ‘couch potato’ troubled people with Type 1, now well-established as an autoimmune condition which they had no ‘choice’ in developing. This perception was not only a new and upsetting stigma for all people with diabetes, but a threat to advocacy efforts: enabling children to live a full life despite their diabetes would attract more sympathy than people who had supposedly engaged in poor lifestyle choices. The formation of Diabetes Youth in 1991 was, in part, a reflection of these growing distinctions.

Yet policy-makers, and the expert committees which advised them, viewed patient self-sufficiency, encompassed within an integrated disease management approach to both forms of diabetes as the best way to improve population health and curtail the rising costs of the disorder to the health system in the 1990s. That the National government, intent on cutting welfare and health spending more generally, came to allocate specific funding for these diabetes management strategies in 1999, spoke to the political acceptability of an approach to public health which focused on reorganising health services, target-setting and monitoring care. As Martin Moore found in Britain, this represented a convergence of a neoliberal government agenda and professionals' development of mechanisms for structured care, rather than government-imposed policy control of professional activity. What Moore described as a 'target-guideline-audit approach to public health' marginalised broader issues such as inequality in official public health policy; in New Zealand, however, targeting resources to Maori health development in diabetes was seen as a way to deal with the most persistent inequalities.⁵ In line with the 1986 Ottawa Charter for Health Promotion, the Ministry of Health also considered the need for 'healthy public policy' to address diabetes. Nonetheless, it concluded that it 'would be difficult or impossible to achieve' the interventionist taxation and regulatory policies that targeted the food industry, which a growing number of advocates, who drew lessons from tobacco control, believed were necessary to counteract the 'obesogenic environment'.⁶

Self-sufficiency was, however, a philosophy centred on empowerment, and as such aligned with the adoption of community development as a public health technique that informed South Auckland's response to diabetes. These community-driven solutions, with Maori and

⁵ Martin Moore, 'A Question of Control? Managing Diabetes and Its Professionals in Britain, c.1910–1994', PhD thesis, University of Warwick, 2014, p.269.

⁶ Ministry of Health, *Diabetes Prevention and Control: The Background Paper: The Public Health Issues*, Wellington, 1997, p.22.

Pacific philosophical underpinnings, focused on diabetes education, health promotion, and employment opportunities, and were personified in the diabetes community health worker schemes of the 1980s and 1990s. These demonstrated wider public health trends that stemmed from the Maori self-determination and international primary care and health promotion movements which stressed local action and community collaboration for grassroots solutions. They also reflected a new research agenda into the prevention of diabetes in high prevalence communities. Distinctively, South Auckland's approach to diabetes emphasised socio-economic determinants of health: as Dr Paparaangi Reid noted in her 1981 report on training lay health workers, the answer to diabetes 'was not to put all of Otara on a diet' but to move Maori out of the lower class with good jobs and educational opportunities.⁷ Community development focused on giving marginalised people tools so they could exercise greater power over their lives; it was therefore easily transformed in a neoliberal era to suit a political agenda for increased withdrawal of state responsibility for social welfare. Progress made under the South Auckland approach was countered by the disruptions and underfunding of the health reforms and, more generally, the increase in poverty exacerbated by central government's social and economic policies.

Although elements of New Zealand's responses to diabetes were predicated on the influence of Maori and Pacific communities, and the country's specific history of the welfare state, for the most part, they sat within broad international trends. A key finding of this study has been the important influence of international networks and exchange in the areas of research, advocacy and policy-making. In the 1960s, the WHO became involved in Prior's epidemiological research and influenced the direction of Dr Donald Beaven's Rangiora survey and screening policy. Beaven was New Zealand's representative for the WHO Western

⁷ Mary Jane P. Reid, 'Elective Report: Training Community Educators in Nutrition, Obesity and Diabetes', 1981, p.5, Health Services Research Committee, 22 February 1982, YCBN 5805 9/b, Archives New Zealand, Auckland.

Pacific Region and advised Pacific nations on establishing services in the 1980s. While Beaven led advocacy efforts for the establishment of the United States model of control plans and research and training centres in the 1980s, consumer and professional group advocacy of WHO and International Diabetes Federation (IDF) resolutions, and the Public Health Commission's WHO derived policy models, were critical to policy formation in the 1990s. The Diabetic Association and its Medical Advisors, then the NZSSD, regularly brought over experts for conferences and public events, and IDF meetings were an opportunity for both lay and professional exchange of ideas. New Zealand approaches to diabetes – sometimes rejecting, but more often following – always drew on overseas experience, particularly American, British and Australian, which gives this study wider significance to the growing historical literature on diabetes and late twentieth century public health.

As the first academic history of diabetes in New Zealand, focusing on voluntary-government interaction in public health responses, this study has only touched on issues which could be further developed. While beginning a discussion of the perspectives of diabetes nurses and dietitians, these health professionals, who were mainstay of diabetes care throughout the twentieth century, deserve far more attention than they have hitherto received in histories of diabetes. Another under-studied area is the history of diabetes in pregnancy. This topic would profit from further examination in its relationship to social policy and public health, considering the importance placed on women's roles as mothers, securing family life and children's well-being had for much of the twentieth century.⁸

Ninety years ago, Dr L.C. McNickle expressed the first public health concerns about increasing, though often hidden, human, social and economic costs of diabetes in New

⁸ Chris Feudtner's history of juvenile diabetes had one chapter considering the expansion of management principles in diabetic pregnancy told through Joslin's patient stories: Chris Feudtner, *Bittersweet: Insulin and the Transformation of Illness*, Chapel Hill, 2003, pp.146–68.

Zealand. Today the Ministry of Health reports some 240,000 New Zealanders have diagnosed diabetes and it believes a further 100,000 have undiagnosed diabetes.⁹ Pacific people are more likely to be undiagnosed than other ethnicities. The latest epidemiological study suggests the national prevalence of diabetes is 7 per cent and that 25 per cent of the population have ‘prediabetes’, which has a high chance of progressing to Type 2 diabetes without intervention. Diabetes is the sixth leading cause of death overall and the fourth for Maori.¹⁰ Just as McNickle had found in 1925, researchers still consider these statistics underestimate the diabetes problem because of the condition’s unattributed contribution to other major causes of death. This thesis then ends where it began, with McNickle’s statement that ‘diabetes is of growing importance in this country, and, as it strikes one as an essentially preventable disease, it is time something was done to prevent it’.¹¹ While public health advocates continue to agree with McNickle’s solutions of early diagnosis and prevention of obesity, as this history suggests, the evidence-based approaches they promote to achieve these ends will most likely be mediated through the policy-making process and the social and political values of the time.

⁹ Ministry of Health, *Virtual Diabetes Register*, updated 26 January 2015, URL: <http://www.health.govt.nz/our-work/diseases-and-conditions/diabetes/about-diabetes/virtual-diabetes-register-vdr>, accessed 26 March 2015.

¹⁰ Kirsten J. Coppel, Jim I. Mann, Sheila M. Williams, Emmanuel Jo, Paul L. Drury, Jody Miller and Winsome R. Parnell, ‘Prevalence of diagnosed and undiagnosed diabetes and prediabetes in New Zealand: findings from the 2008/09 Adult Nutrition Survey’, *New Zealand Medical Journal* (NZMJ), 126, 1370, 1 March 2013, pp.23–42.

¹¹ L.C. McNickle, ‘Diabetes in New Zealand – discussed etiologically’, *NZMJ*, 24, 1925, p.245.

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