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# Continence Services in New Zealand

History, Services, Costs and Impacts

A Call for Action Paper  
September 2009



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*“Incontinence is a complex issue with physical, social and monetary connotations that may diversely affect people across the human lifespan. Resolution of incontinence is not possible for a considerable proportion of these people and they rely on continence products to achieve social continence”.*

Source: Page 5, Position Paper: Toward an Equitable National Subsidy Scheme for Continence Products.  
Continence Foundation of Australia. November 2000

*“Yes it is, it is a serious problem to me, because of how I feel, I feel shame and to my husband as well and to my family as well. It is a big problem for me. Even now, I have not told anybody about this problem..... My husband, yes even my husband I never told him”.*

28 year old Pacific Island woman

*“Unfortunately my need for disposable diapers got out and everything went downhill. Construction workers aren’t the most easy-going bunch. I had lost the respect of the crews and therefore couldn’t do my job anymore. The owner called me in to his office and laid me off for lack of work in our busiest year”*

Construction Worker

## Executive Summary

### Introduction

This paper is to act as a call for action and a stock take of the history and current status of continence services and funding in New Zealand, and is concerned with urinary and anal incontinence, of all types and severities and across all ages. In line with international developments, it informs the future development of a national continence plan of action for New Zealand and to assist government and District Health Boards (DHBs) with policy and planning to improve services and reduce the current access inequalities. This is especially important at this time due to increases being reported in incontinence issues in children and youth and the government policies of older people staying at home longer, along with the ageing population projections. New Zealand's population aged over 65 years is predicted to increase from 12% of the population at the 2006 census to 25% in 2051<sup>1</sup>.

Urinary incontinence is defined by the Standardisation Committee of the International Continence Society as *"The complaint of any involuntary leakage of urine"*. A corresponding definition can also apply to anal incontinence, the complaint of the involuntary loss of solid or liquid faeces or gas. Due to stigma and embarrassment incontinence is often unreported. Many studies show that two-thirds of people do not report their own or their child's incontinence issues to their health professional.

Incontinence has a major impact on many parts of a person's life. It has physical and social ramifications such as schooling, urinary tract infections, odour, skin infections, embarrassment, discomfort, loss of self-esteem, depression and social isolation. Children can be bullied by siblings or peers because of it and there may be safety risks for them (abuse). Incontinence affects social interactions, sex life, ability to work, travel, play sports and participation in family and community life. Incontinence is also a problem for many carers who frequently play a role in physical care, and with the cleaning consequences of incontinence, as well as selecting, purchasing, arranging delivery for, paying for, and helping to apply continence products.

### Prevalence

Urinary and anal incontinence are highly prevalent conditions. Based on estimates from New Zealand research and extrapolation from international research there are at least:

- 590,000 New Zealanders of all ages with urinary incontinence
- 340,000 New Zealanders with anal incontinence

As incontinence problems are more prevalent in older adults these numbers are likely to increase markedly as the population ages. New Zealand prevalence figures for children and youth show that by age eight 3.3% of children had failed to gain bladder control and 7.4% still had nocturnal enuresis

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<sup>1</sup> Source: Statistics New Zealand based on the 2006 census.

(bedwetting). By age 11 the figure was reduced to 6% with bedwetting. In the United Kingdom it is known that 1 in 12 young people struggle with bedwetting, daytime wetting, constipation and soiling<sup>2</sup>.

There has been one study on prevalence noting the differences for Maori and Pacific Island women, in Wellington. It noted overall 34% prevalence with a slightly higher percentage (47%) for Maori, 31% for European and 29% for Pacific Island women<sup>3</sup>.

Also, in New Zealand there are approximately 420,000 carers who look after sick or disabled family members, including children, many of whom have incontinence problems. Caring for incontinence puts additional stress and burden on those carers. In an online survey<sup>4</sup> (August 2009) for carers about government information more than 40% of 491 carers requested information about how continence services work in New Zealand, and how to access aids and supplies.


### Emotional and Psychological Consequences of Incontinence

There are significant and often devastating impacts on the physical and emotional health of people with incontinence issues. It can be humiliating, restrict activity including schooling, intimate relations and employment options. Vigod, S and Steward DE in a 2006 study note that for women (age 18-44) with urinary incontinence 30% in age 18 – 44 years have depression compared to only 9.2% in women without urinary incontinence.

Reported rates of child punishment are 20 to 30 percent with an increased risk of physical abuse. Recent high profile child abuse cases in New Zealand, leading to death, have involved enuresis and toileting issues<sup>5</sup>.

### History of Continence Services in New Zealand

Organised continence services are relatively new in New Zealand and internationally. The timeline for development in New Zealand is:



Early 1980's	1986	1986 - 1989	1989	Mid 1990's	1996	January 2001	2001 & 2003
Emerging professional interest in continence	Establishment of the Auckland Continence Advisor Group	Establishment of Wellington, Christchurch and Otago groups	Establishment of NZCA	Development of the first national continence service specification begins	Aged residential care providers required to provide continence supplies	DHBs established	2001: Development of mandatory nationwide service specifications  2003: Review of nationwide specifications

<sup>2</sup> [www.eric.org.uk](http://www.eric.org.uk)

<sup>3</sup> Lara and Nacey. Ethnic Differences Between Pacific Island, Maori and European Women in prevalence and attitudes to urinary incontinence. New Zealand Medical Journal, 107 (986): p 374 – 6. 1994.

<sup>4</sup> [www.carers.net.nz](http://www.carers.net.nz)

<sup>5</sup> Tsang, B (Dr). Nocturnal Enuresis. New Zealand Doctor, 2006. 17 – 21.

However services remain fragmented and inequitable across the country, in many cases not providing enough treatment and / or products to support needs and quality of life.

### **Current Services**

Services include assessment, treatment (including information), surgery, management products and advice to family and carers. Services are provided mainly via District Health Boards (DHBs) from Community Services, some Public Health services and Urology Departments. DHBs are contracted via a national service specification, which is interpreted and delivered at a local level, causing significant variation in access and service delivery across New Zealand. There is one publically funded contract (as opposed to the service being with the DHB) with Nurse Maude in Christchurch, who also delivers ostomy services. Services for children are often provided out of adult services, which is not best practice. A few continence advisors provide services privately.

For those living in long stay younger person's residential care, all continence services are via DHBs. For those in aged residential care the (product only) service is included in the price. Assessment and treatment services are meant to be accessed from community based DHB services. However in reality it is very difficult for services to be accessed due to the relatively small numbers of continence advisors and high demand.

Services are highly variable across the country in terms of waiting times, what is provided and interpretation of the national service specification. For example, in some areas advisors don't have specific expertise on incontinence issues for children, so choose not to treat them. Also for some, no products are provided for up to six months post surgery or treatment, irrelevant of need or impact on a person's life. In others one product (pad) per day is allocated which also may fall well short of need and in others more products are provided. Individuals or families need to purchase their own. In effect the budget management or rationing practices of different DHBs render the services somewhat ineffective and inequitable, inducing additional stress for individuals and/ or families. This is not the case with ostomy supplies which are reported to be of a reasonable volume.

### **Professional Training and Education**

In 2000 till 2005 there was a multidisciplinary, extra mural Post Graduate Certificate course run from University of Otago via the Department of Health Sciences. It stopped due to lack of applicants however is taking a new intake for the 2010 year. Australia also offers training which some people take up, but it is seen as an expensive option. People generally prefer a New Zealand run course as many DHBs don't provide funding for courses like this, for their staff outside of New Zealand.

The NZCA run courses and education seminars and have just completed a national road show of these. Attendees cover a wide range of health professionals and teachers. The Continence and Women's Special Interest Group of the New Zealand Society of Physiotherapists run some courses on incontinence for members. For general up-skilling there are also some courses via polytechnics.

## **Costs of Incontinence**

Costs are evident in both direct and indirect terms. Examples of direct costs are government funded services, laundry, medications, home care, surgery, long term care, longer stays in hospital, extra nappies, toilet paper and towels and cleaning of carpets, mattresses and couches.

It is estimated that the total annual costs of incontinence in New Zealand are:

- Treatment and personal: \$142 million (urinary only)
- Loss of employer and work place productivity: \$2.1 billion

Total \$2.242 billion.

Employer and workplace loss of productivity include, but are not limited to, absenteeism and presenteeism – i.e. lack of concentration, taking more toilet breaks and decreased number of hours worked.

## **Imperative to Change**

There are high direct and indirect fiscal costs to both public funds and individuals which are highly inequitable across New Zealand. Couple this with the ageing population and there is significant fiscal risk to both government and individuals. Australia studies estimate expenditure for incontinence will increase by 201%, due to the ageing population.

There is a critical need to improve assessment, treatment and management (products) services in New Zealand and address the inequities in access to services and health outcomes.

## **Recommendations: National Continence Policy and Plan**

To improve continence services and outcomes for New Zealanders it is recommended that the Minister:

1. Direct the Ministry of Health to develop, in partnership with the New Zealand Continence Association and the New Zealand Carers Alliance, a National Continence Policy and Action Plan to guide and coordinate investment, service improvement and provide for measurable outcomes
2. Direct the Ministry of Health to improve assessment and treatment for incontinence, and management (products) of incontinence
3. Direct the Ministry of Health to develop equitable access to incontinence services via consistent service delivery models, increased volumes and improved quality
4. Agrees that investment in educating more health professionals – both general health professionals (e.g. GPs, public health nurses, social workers) and dedicated incontinence specialist staff is a priority

5. Direct the Ministry of Health to carry out its commitments under the Carers Strategy Action Plan to improve learning for informal (family) carers so they can carry out their role more safely
6. Agrees to the need for more work on understanding the incontinence prevalence and needs of Maori and Pacific Island people in New Zealand

As a second tier priority:

7. Agrees to an increase in public awareness strategies
8. Direct the Ministry of Health to facilitate the development of a Best Practice Guideline, in partnership with the New Zealand Continence Association and the New Zealand Carers Alliance

# 1 Introduction

## 1.1 Purpose

This paper is to act as a statement and stock take paper of the history and current status of continence services and funding in New Zealand. It is intended it will inform the future development of a national Continence Action Plan for New Zealand and assist government and District Health Boards (DHBs) with policy and planning to improve services and reduce the current access inequalities. Unlike the United Kingdom and Australia, New Zealand does not have a national continence strategy.

## 1.2 Methodology

The New Zealand Continence Association engaged an independent contractor to undertake the development of this paper. Information was sourced via:

- International and national literature
- Web searches on bowel and bladder sites
- Search of the New Zealand Ministry of Health Web site
- Search of the Nationwide Service Framework Library
- Interviews with key stakeholders. A list of those interviewed is attached as Appendix One.
- Liaison with the Continence Foundation Australia

This paper covers all types and severity of continence issues: urinary, anal, and the combination of the two, and across all ages. For the purposes of this paper anal incontinence refers to both incontinence of liquid or solid faeces, and / or gas. Older literature usually refers to just faecal incontinence without distinguishing these types.

## 1.3 Definition and Impact of Continence

Incontinence has been defined by the Standardisation Committee of the International Continence Society as:

*“The complaint of any involuntary leakage of urine”.*

A corresponding definition can also apply to anal incontinence, the complaint of the involuntary loss of solid or liquid faeces, or gas. Due to stigma and embarrassment incontinence is often unreported. Many studies show that two-thirds of people do not report their continence issues to their health professional.

Incontinence affects many parts of a person’s life. It has physical and social ramifications such as urinary tract infections, odour, and skin infections, embarrassment, discomfort, loss of self-esteem, depression and social isolation. It affects social interactions, sex life, ability to work, travel, play sports and participation in family and community life. Incontinence is also a problem for many carers who frequently play a role in physical care with cleaning the consequences of incontinence, as well as selecting, purchasing, arranging delivery for, paying for, and helping to apply continence products.

There are at least 420,000<sup>6</sup> New Zealanders who care at home for an ill, disabled or elderly family member. Additionally, odour in the home may be a problem, and there is the constant burden of cleaning, laundering, and airing.

Some people with incontinence can be treated, but many more can achieve social continence after appropriate assessment and product trialing (management), which allows them to function freely within the community<sup>7</sup>. Early treatment and behavioural change can mean longer term prevention of ongoing or more significant issues. Two main types of incontinence are:

- Stress incontinence refers to leakage when coughing, laughing or sneezing or with exertion. Usually just a small jet of urine escapes, and it becomes bothersome when it happens frequently. Stress incontinence mainly affects females
- Urge incontinence refers to the leakage that occurs after a strong urge to void and which the person is unable to defer. The amount leaked is often larger and urge incontinence is often more bothersome than other forms of incontinence. Urge incontinence affects both males and females

A mixed pattern of incontinence with features of both stress and urge symptoms can also occur.

Symptoms of incontinence are:

**Table 1: Symptoms of Incontinence**

Bladder symptoms	Bowel symptoms
<ul style="list-style-type: none"> <li>— Leak urine with coughs, sneezes, exercise or on the way to the toilet.</li> <li>— Pass urine frequently.</li> <li>— Rush to the toilet - urgency.</li> <li>— Get up twice or more at night to pass urine.</li> <li>— Wet the bed when asleep.</li> <li>— Feel their bladder is not completely empty.</li> <li>— Poor urine flow.</li> <li>— Strain to get the bladder to empty.</li> <li>— Frequent urinary tract infections.</li> </ul>	<ul style="list-style-type: none"> <li>— Leakage from the bowel with the urge to open their bowels.</li> <li>— Urgency with the urge to open their bowels.</li> <li>— Leakage from the bowel without the urge to open their bowels.</li> <li>— Leakage from the bowel on passing wind.</li> <li>— Unable to control wind.</li> <li>— Straining to empty their bowels.</li> </ul>

Source: Continence Foundation Australia [www.continence.org.au](http://www.continence.org.au)

<sup>6</sup> Source: Census 2006

<sup>7</sup> Position Paper: Toward an Equitable National Subsidy Scheme for Continence Products. Continence Foundation of Australia. November 2000.

## 2 Prevalence

### Overview

Prevalence (i.e. how many people have incontinence at any one time) is difficult to determine accurately because:

- Studies of incontinence use different definitions of the degrees of incontinence
- Definitions are partly subjective
- People under-report the problem due to the stigma and embarrassment
- Studies of prevalence cover widely different populations and are not easily comparable (Hunskar et al 2005)<sup>8</sup>

Incontinence can also vary in severity and can be mild, moderate, severe or very severe<sup>9</sup>.

### Urinary Incontinence

Thom<sup>10</sup> in a review summarised figures for the prevalence of urinary incontinence. This is reflected in Table 2.

**Table 2: Summary prevalence of Urinary Incontinence by Age, Gender and Frequency in Adults**

Group	Ever Urinary Incontinent (Mean)	Daily Urinary Incontinent (Mean)
Older women	34%	12%
Older men	22%	5%
Younger women	25%	Not available
Younger men	5%	Not available

Many studies reflect that for nursing home, or rest home residents, the figure is closer to 50%.

Exact New Zealand prevalence figures for children and youth are harder to obtain. Based on the 1996 census over 50,000 children over age 5 years have nocturnal enuresis (bedwetting). 52% of children have a history of soiling or delayed toilet training after two years of age, 20% of school age children are bed wetting at least twice a week and 2.5% of school age children are wetting at least once a night.

For night time bedwetting the percentages are:

- 15% under 5 years
- 5% under 10 years
- 2% under 15 years
- 1% of adults<sup>11</sup>

<sup>8</sup> Wainwright T. South Island Shared Support Agency (Ltd) Source for defining incontinence: adapted from "A Review of the Need for and Current Organisation of Continence Services in Canterbury. August 2006.

<sup>9</sup> Canadian Continence Association. Impacts of Incontinence in Canada. A Briefing Document for Policy Makers. May 2009

<sup>10</sup> Thom D. Variation in estimates of urinary incontinence prevalence in the community: Effects of differences in definition, population characteristics, and study type. Journal American Geriatric Society. 1998; 46: pages 473-480

<sup>11</sup> Paediatric Society of New Zealand. Best Practice Evidence Based Guidelines Nocturnal Enuresis "Bedwetting". 2005

Bedwetting is more common in boys and day time wetting is more common in girls.

In the United Kingdom it is known that 1 in 12 young people struggle with bedwetting, daytime wetting, constipation and soiling. One study<sup>12</sup> in the United States concluded that in their study with children and youth aged 4 to 17 years, in a primary care setting:

- 22.6% were constipated
- 4.4% were faecally incontinent
- 10.5% were urinary incontinent

Constipation increased the rate of both urinary and faecal incontinence that for those without.

Based on the 2006 Census data population numbers Table 3 extrapolates estimates from a range of prevalence data for the number of people who may have urinary incontinence in New Zealand.

**Table 3: Numbers for Urinary Incontinence in New Zealand Based on 2006 Census Population Statistics<sup>13</sup>**

Population Group	Approximate total NZ population in this group	Approximate prevalence of urinary incontinence in NZ	Approximate number with urinary incontinence
Children (8 to 17 years)	612,000	3.3%	20,200
Younger women (20 to 55 years)	1,007,000	25%	250,000
Younger men (20 to 55 years)	944,448	5%	47,000
Community dwelling older people (55 years plus)	909,000	34% female 22% male	260,000
Residential care older people (55 years plus)	30,000	50%	15,000
<b>TOTAL</b>	<b>3,502,448</b>		<b>590,000</b>

### Faecal Incontinence

Estimates of faecal incontinence are even more difficult to establish.

A study published in June 2008 in the American Journal of Gastroenterology<sup>14</sup> states that of their study 18% of adults over age 18 years are faecally incontinent. A New Zealand study by Lynch AC et al<sup>15</sup>

<sup>12</sup> British Medical Journal. Prevalence Rates for Constipation and faecal and urinary incontinence in childhood. Archives of Disease in Childhood. 2007. 92:486 – 489.

<sup>13</sup> Weatherall M (Dr). Numbers, costs and treatments for Urinary Incontinence in New Zealand. Draft NZCA Report. March 2009

<sup>14</sup> Johanson, J (M.D, M.S, F.A.C.G) and Lafferty, J (RN). American Journal of Gastroenterology. Vol 91, Issue 1, pg 33-26. June 2008.

<sup>15</sup> Lynch AC et al, The prevalence of faecal incontinence and constipation in a general New Zealand population. NZ Medical Journal 2001;114:474-7

showed that faecal incontinence affected the lifestyle of 8.1%. The 8% figure is the same for Australia (if flatus is excluded. If it is included it is 35%).

A systematic review of the prevalence of faecal incontinence undertaken by Auckland University<sup>16</sup> in 2004 looked at 16 studies. The conclusion was that there needs to be a consensus definition of faecal incontinence before prevalence can be determined. However the studies indicated that the prevalence could be between 0.4% to 18%.

From the web site *About Incontinence*<sup>17</sup> the following shows:

**“Fecal incontinence affects people of all ages.**

In women living in the community, fecal incontinence occurs in 6% of those younger than 40 and increases to 15% in older women. Combined fecal and urinary incontinence is estimated to occur in about 10% of women

In men living in the community, fecal incontinence occurs in 6–10% and increases slightly with age. Combined fecal and urinary incontinence occur in 10% of men

Two nursing home studies have identified a 45.0% to 47.0% prevalence of fecal incontinence among residents. Studies suggest that incontinence contributes to the decision to institutionalize elderly patients

Minor fecal incontinence (staining underclothes or losing less than 2 tsp. of stool) affects 7.4% of adult males and 6.9% of adult females

Approximately 30% of people with irritable bowel syndrome (IBS) have frequent loose stools and 20% report fecal incontinence

Obstetrical trauma, leading to sphincter muscle injury or pudendal nerve injury, is a common cause of fecal incontinence”.

A 1990 United Kingdom survey of incontinence in older people in long-term care found that around 40% of people in long-term hospital and in psycho-geriatric facilities were faecally incontinent, mostly in combination with urinary incontinence. Around 15% of people living in rest home level facilities were faecally incontinent, again mostly in combination with urinary incontinence. (Peet et al 1995).

A United Kingdom Department of Health (2001) report estimates faecal incontinence to be present in 10% of rest home residents, 30% of long-stay hospital residents and 60% of those living in specialist dementia facilities.

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<sup>16</sup> Macmillan, A; Merrie, A; Marshall, R; and Parry, B. University of Auckland. June 2004.

<sup>17</sup> <http://www.aboutincontinence.org/site/about-incontinence/prevalence/>

So, if it was to be assumed that the estimate was about 8.1% for those living in the community (based from the New Zealand study) and an average of 30% for those in older person's residential care then based on the 2006 census population figures of 4,143,282, assuming 30,000 live in residential care that would equate to a total of 342,175 people with faecal incontinence.

## Summary

So while it is difficult to be exact in prevalence it is obvious that there are a large number of New Zealanders living with incontinence. The two totals of urinary and faecal incontinence cannot simply be added as some people have both.

With the ageing population and the fact that incontinence increases with age, although it is not directly related to age, supporting people with incontinence issues will become an increasing challenge to the public sector.

## 3 Emotional and Psychological Consequences of Incontinence

“Incontinence takes a serious emotional toll on those living with the condition”<sup>18</sup>.

Most studies outline the emotional and psychological consequences of incontinence. The impacts range from stigma to embarrassment, social isolation, depression, shame, guilt and loss of self esteem.

The following range of statements reflects the type of comments in the literature<sup>19</sup>:

- Contreras Ortiz, O. 2004. “Urinary Incontinence is a common problem, affecting women in all age groups, and has devastating effects on their social, professional and family life”
- Farage M.A et al: 2008. “Significant and often devastating impact on the physical and emotional health of the patient. Incontinence in the older adult is a humiliating and disabling disorder which causes substantial stress, depression and limitation. It can impede interpersonal relationships, decrease sexual function and increase the risks of debilitating falls, institutionalization and even increase mortality”
- Vigod S, Steward DE. 2006. “The prevalence of depression was 15.5% in women with urinary incontinence (30% in women ages 18-44) and only 9.2% in women without urinary incontinence”
- Viktrup L, et al: 2005. “Urinary incontinence in the elderly is a significant health problem fraught with isolation, depression and an increased risk of institutionalization and medical complications....”

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<sup>18</sup> The Canadian Continence Foundation. Impacts of Incontinence, May 2009, page 6

<sup>19</sup> The Canadian Continence Foundation. Impacts of Incontinence, May 2009, pages 7-9

Dr Bobby Tsang in his 2006 New Zealand Doctor Article states:

“The stigma and effects of this can be devastating and increase with age. Repercussions include humiliation, bewilderment, loss of self esteem and behavioural problems. The child’s embarrassment leads to avoidance of sleepovers, camps or inviting friends to play or stay over. Scholastic achievement and later sexual activity may also be affected. The stress of caring for a child with nocturnal enuresis can cause parents/ caregivers anxiety and guilt..... Reported rates of child punishment are 20 to 30 percent with an increased risk of physical abuse. Recent high profile child abuse cases in New Zealand, leading to death, have involved enuresis and toileting issues”.

## 4 History of Continence Services in New Zealand

### 4.1 The New Zealand Continence Association

Historically continence has been a silent issue, whereas ostomy<sup>20</sup> has been not so hidden. Nurses who had knowledge on ostomy were located in generic District Nursing services. In the early 1980s some concerned health professionals started considering how services could be improved for ostomy patients and also started looking at how to start and improve incontinence services as well.

The New Zealand Continence Association (NZCA) was originally incorporated in 1986 as the Association of Continence Advisors (Auckland) Inc. Membership consisted mostly of concerned health professionals who wanted to learn more about urinary incontinence and in promoting public awareness of this remediable, generally ignored and potentially embarrassing medical condition. There was one employed continence advisor whose salary was funded half by the local district nursing service and the other half via funds from the recent Telethon (which was for the Year of the Aged).

After that separate groups formed in Wellington, Christchurch and Dunedin. In 1989 it was established that there was a need for a national organization. The Association of Continence Advisors was developed into a national and multi-disciplinary organisation in 1991 and renamed the New Zealand Continence Association (NZCA).

The NZCA was established to provide a service to incontinence sufferers, caregivers, health professionals and the general public by providing information and education on topics of incontinence. Since its establishment in 1986 the NZCA now has a governance structure including a National Executive and a Chief Operating Officer. They maintain a web site ([www.continence.org.nz](http://www.continence.org.nz)) and a toll free 0800 continence advisory number. The current mission of the Association is to:

“Improve the standard of healthcare delivery, to those with bladder or bowel incontinence dwelling in the community, in rest homes or hospital settings in New Zealand”.

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<sup>20</sup> Definition: **Ostomy** - An operation to create an opening from an area inside the body to the outside. [www.medterms.com](http://www.medterms.com)

In the 12 months to June 2009 the NZCA received 597 calls to the helpline. For many it is the first time they have spoken about their continence issues. Over the past few years there has been a drop in the calls to the phone line and an increase in hits on the web site. A similar pattern has been seen in Australia. This is in line with changing use of on line options but also people feeling shy and embarrassed about discussing their issues.

The NZCA has provided free continence education session to 1,600 carers, nurses and other health professionals across New Zealand throughout 2009. This will be repeated in 2010.

## **4.2 Nationwide Service Specification Development**

### **Community Services**

Community incontinence services are typically delivered through District Health Boards (DHBs) and from a few privately run services, e.g. physiotherapists. The DHB services are governed by a nationwide service specification that details what services and how should be provided.

The original development of a specification was in the Regional Health Authority time, in the mid 1990's. A nationwide working group, led by the Southern Regional Health Authority, was set up to discuss and develop the specification. This specification has developed over time but it is not widely accepted<sup>21</sup> as good practice and was updated in 2001, and again in 2003. However the latest revision has not been agreed by the DHBs and is not mandatory.

Coordinated nationwide service development has not been evident across DHBs and a large variance in what assessment and treatment services, waiting times and products are available was established and this remains today.

### **Disability Support Services**

Publically funded disability support services are available for people with a long term (over 6 months) intellectual, physical or sensory, or a combination of those, disabilities. Disability support services transferred from Vote: Welfare to Vote: Health in the 1990's. At that time this included "Prescribed amounts of disposable items like continence products and ostomy supplies"<sup>22</sup>. This service was via District Nursing services but it is not clear how, or if, Disability Support Services paid separately to Health for this. The Ministry of Health is currently undertaking work looking at the history of funding devolution.

When the nationwide Continence Service Specification was developed in 2003 all responsibility for incontinence services was developed to DHBs. Disability Support Services no longer had any responsibility, except for those people who had been reintegrated into the community from long term institutions, e.g. Kimberly.

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<sup>21</sup> Information received via interviews with experts and others working in the field of continence, during the development of this paper.

<sup>22</sup> "Who gets Disability Support Services and When do you pay?" Ministry of Health, July 1995.

## Aged Residential Care Services

In addition for government subsidised residents of rest home and long stay hospital care incontinence products were required by the four Regional Health Authorities' service specifications for all levels of care. In the August 1996 central service specification from Regional Health Authorities for Dementia Care, and therefore for rest home care also and it says:

### “3.4 Personal Care

The service provides assistance with personal care appropriate to the individual needs of each subsidised resident: Continence aids such as pads, urodomes, bed protection, catheter bags and catheters which must be used appropriately”.

## District Health Boards

DHBs came in to being in 2001. Over the following two years they took responsibility for full planning and funding and for their provider arms, the Hospital and Health Services. This included the services that provide assessment, treatment and management of continence services. Funding for aged residential care services was devolved to DHBs by the Ministry of Health in 2003.

## 4.3 Summary Timeline

A summary timeline of development of services and DHBs is below as Graph 1.

**Graph 1: Summary of Development Timeline**

Early 1980's	1986	1986 - 1989	1989	Mid 1990's	1996	January 2001	2001 & 2003
Emerging professional interest in continence	Establishment of the Auckland Continence Advisor Group	Establishment of Wellington, Christchurch and Otago groups	Establishment of NZCA	Development of the first national continence service specification begins	Aged residential care providers required to provide continence supplies	DHBs established	2001: Development of mandatory nationwide service specifications  2003: Review of nationwide specifications

## 5 The Current System in New Zealand

### 5.1 What services are available

#### Service Description

Continence services cover:

- assessment
- treatment (e.g. advice, exercises, behavioral changes and medications)
- surgery (e.g. sling procedures for stress incontinence, transvaginal needle suspension and retropubic procedures) and
- products (e.g. pads, urodomes, catheters, gloves, briefs, night bags, catheter valves)
- advice to carers and family

Services are mainly delivered by District Health Boards (DHBs), Nurse Maude in Christchurch, with some private practitioners undertaking services also. Services in DHBs are usually located within Community Health services with continence advisors being nurses or physiotherapists. Urology departments also have involvement with surgical, treatment and advice options.

#### ACC

For ACC clients all continence needs are assessed by a specialist continence nurse, contracted by ACC. The ACC case manager will make the decision on what services will be funded based on the nurse's assessment. Treatment depends on what is required and may be delivered by the public system in some acute circumstances or other services as contracted by ACC. Prescribed products are then provided directly to the client's home by a contracted supplier to ACC.

#### Public Service Specifications and Services

There is a nationwide service specification for Continence Services, available at the Nationwide Service Framework Library<sup>23</sup>. The specification covers what services are expected and for whom, as well as service linkages, exclusions, quality requirements, a risk assessment framework and a section on supply of consumables (products). This is intended to be a guide only however anecdotal evidence shows a large variation in interpretation of it, especially in the delivery of products. For example it states:

- "Pads; 350 ml capacity and up; 1-4 per day"

However, irrelevant of need, some people are allocated only 1 pad per day and others can get as many as they need depending on the DHB's local policy and management. The specification does detail that the numbers are a guide only and that more products, or different types, may need to be used based on need. A copy of the Supply of Consumables page is attached as Appendix Two.

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<sup>23</sup> <http://www.moh.govt.nz/moh.nsf/indexmh/dhbfundingperformance-nsf>

In the health sector there is wide spread dissatisfaction with the specification especially the requirement for leakage of 400 mls of urine before a product is provided free of charge. This amount is not evidence based and in the sector is deemed inappropriate (too high).

Due to the restricted numbers of products supplied by the health system, people then need to pay privately to meet their needs. Some people may be eligible for the Disability Allowance which is administered by Work and Income to assist with the cost of these supplies. Currently the allowance is up to \$55.88 per week. This amount is inclusive of other disability related costs such as travel, health etc.

Following in Table 4 are some actual examples of people's recent experiences.

Table 4: Recent New Zealand Actual Experiences

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**Mr X**

**Incontinence post prostate surgery and has been told he cannot get any funded supplies for 6 months. He has been told that as he is likely to be incontinent for 6 months there are no products during that period.**

**He has applied to Work and Income in May 2009 but no resolution at this point.**

**He is finding the cost of products and related travel costs a burden, especially as he is self employed.**

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**Continence Advisor "Y" – Employed in a large DHB**

**Continence advisor "Y" was told in September 2009 that each new client will only receive one product per day.**

**The advisor sees a lot of patients already who need to access Work and Income but finds it a problem that often the wealthiest, who have Family Trusts, are actually the ones who can receive Work and Income support.**

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**Daughter with Mother diagnosed with rare sudden onset of dementia**

**Mother started wetting the bed every night and the GP couldn't give them any advice about what to do. From another source she found out how to contact a continence advisor. However the advisor's waiting list was 3 weeks, although she marked this case as urgent.**

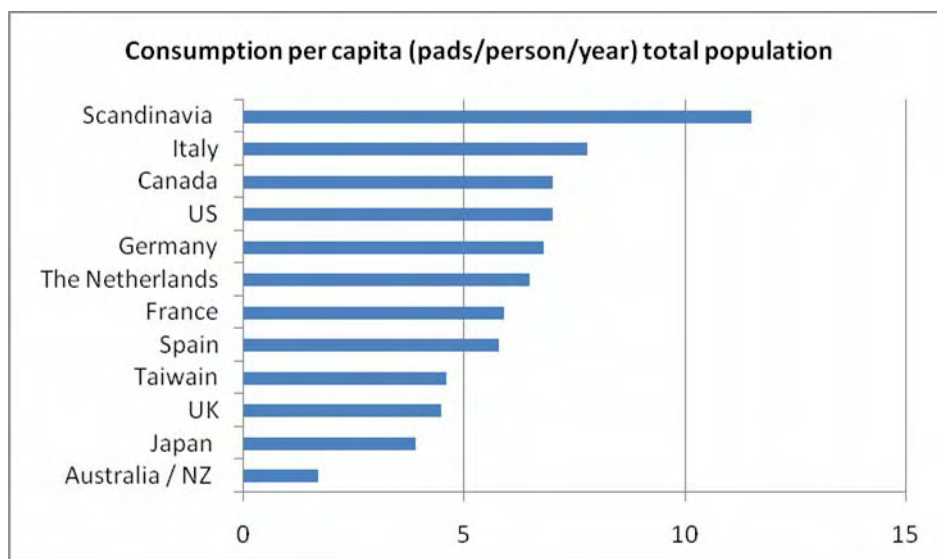
**The advisor gave them the name and number of an incontinence product company to call and told them what product to ask for. However the company was out of stock.**

**The daughter also has two preschoolers in nappies so the additional washing was extremely stressful.**

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An article on the economics of incontinence<sup>24</sup> shows the numbers of heavy duty incontinence pads per capita used in different countries.

Graph 2: Consumption of Pads Per Person Per Year



Source: Recreated and adapted from Economics of Incontinence, page 975.

### Aged Residential Care

For eligible<sup>25</sup> residents of aged care services those services are required to provide incontinence products, but not assessment or treatment services. The level of delivery of products is hugely variable and there is much anecdotal evidence of people being wet due to lack of attention to their individual needs. Loss of dignity and other health issues come with being wet, such as skin irritations and urinary tract infections.

The current aged residential care contract has reference to continence supplies, requiring providers to:

#### “D 18.4 Provision of Continence Supplies

.....have to be of an appropriate standard..... Able to seek advice from the community services – from the continence advisor if one is available”.

This excludes regular specialised incontinence assessment and treatment options, to try and reverse or maintain current continence status. For example change of medications, regular toileting.

In reality there is a variance in the quality and amount of supplies given and some individuals or families choose to purchase their own to ensure improved dignity and less wetness for the person. It is rare for

<sup>24</sup> The Economics of Incontinence. Committee 14. Consultant: Joseph Ouslander. Chapter 14, p 965 (not dated).

<sup>25</sup> While the Aged Related Residential Care contract (ARRC) refers to subsidised residents, in fact all residents who have been assessed by a NASC as requiring rest home or hospital level of care indefinitely, are entitled to receive contracted care services set out in the ARRC contract, irrespective of whether a funder has any liability to pay for any of the cost of that person's care - refer Section 6(3) of the Social Security (Long-term Residential Care) Amendment Act 2006.

the aged care sector to be able access community based continence advisors due to the scarcity of advisors, who then prioritise community based patients.

## Ostomy

There are approximately 5,000 people with an ostomy in New Zealand. Like continence services, health funded ostomy services are covered through a contractual service specification via DHBs. This specification also notes a suggested supply amount for product. It is reported by users that overall the allowance is reasonable if the client uses practical management strategies in line with the product specifications. Services are generally provided via a stoma nurse in district nursing services. The exception is via Nurse Maude in Canterbury which is contracted by the DHB to undertake this service.

People in aged residential care facilities can also access these services.

## 5.2 Funding and Costs

DHBs are funded via a Crown Funding Agreement and services required are detailed in the Service Coverage Schedule. This schedule describes the minimum range of health and disability support services the District Health Board must provide for its population. The Service Coverage Schedule is promulgated by the Ministry of Health and is a national standard. It includes: Maori health, mental health, personal health (primary, secondary and limited tertiary), public health and disability support services.

In addition to the continence advisory and management roles the DHBs also undertake surgical interventions to reverse or reduce the impact of incontinence. Volumes for the following three codes for the past four consecutive years are detailed in Table 5.

Table 5: ICD-10 Version 3 Procedure Codes

Code	Text Description
3559900	Sling procedure for stress incontinence
3704300	Transvaginal needle suspension for stress incontinence
3704401	Retropubic procedure for stress incontinence

## 5.3 Professional Education and Training

Prior to the establishment of the NZCA there was little or no coordinated training programmes.

In 2000 till 2005 there was a multidisciplinary extra mural Post Graduate Certificate course run from University of Otago via the Department of Health Sciences. It stopped due to lack of applicants however is taking a new intake for the 2010 year. Australia also offers training which some people take up, but it is seen as an expensive option.

The NZCA run courses and education seminars and have just completed a national road show, delivering free education sessions to 1,600 carers, nurses and other health professionals. This will be repeated in

2010. The NZCA is investigating the option of providing education through an e-learning site to increase the reach and decrease the costs.

The Continence and Women's Special Interest Group of the New Zealand Society of Physiotherapists run some courses on incontinence for members. For general up-skilling there are also some courses via polytechnics.

## **6 Issues with the Services and Imperative for Change**

### **6.1 NZCA: Issues with Services**

The NZCA in a paper to the New Zealand Carers Alliance, February 2009, notes 11 key issues with the current services:

1. Lack of equity of product provision and services across DHBs
2. Assessment and treatment services differ depending on DHB region and geographical difficulties
3. Lack of education of health professionals, support workers, families with health and disability needs, services and appropriate referral pathways. Specialist services are frequently not offered to the consumer
4. Differentiation between accident and illness precipitated incontinence in level of service and product provided
5. Other co-morbidities treated before incontinence
6. Quality control issues in institutional care
7. Community dwelling older people not able to access same care as those in residential care
8. Those with incontinence greater than six months should be classed as a disability
9. Elderly versus disabled – elderly are disadvantaged
10. Lack of recognition of the psychological, social and economic as well as physical impact of incontinence on the life of the sufferer and their families
11. Lack of flexibility and choice for families who are experienced continence consumers to have a say in how resources (about products for example) are allocated for their need

In summary, this reflects a lack of overall awareness of continence issues, the impacts on individuals and families as well as national inequities in services available.

### **6.2 Consumers**

In November 2007 a NZCA Stakeholder group of consumers and health professionals was held. The Consumer and Carer Panel identified a large range of issues. In summary these were:

- Humiliation, embarrassment, shame and often anger
- Lack of dignity and respect especially where product supply is concerned

- Lack of advice on sexuality issues and relationships suffer
- Poor communication from health professionals
- Lack of access: to appropriate interventions, basic surgery, services and products
- The difference between accident or illness caused incontinence
- Lack of awareness of continence issues – both for frontline health professionals and general public
- Follow ups are on the phone and not face to face
- The carer has to become experts in continence care and feel stress and weariness
- Lack of toilet maps nationwide

In June 1999 a report titled *“Urinary Incontinence: A Qualitative Approach”* was published by the Department of Women’s Health, South Auckland Health<sup>26</sup>. The reports notes that incontinence is still widely thought to be a taboo subject and that it is inevitable and irremediable, and that women have to “put up with it”.

The report notes the impact on women of incontinence to be:

- Not being able to participate in family activities
- Fear of leaving the house in case they have an “accident”
- Impacts on relationships with their partners / husbands
- Shame and embarrassment on individuals and whole (Pacific) families
- Frustration and depression
- Governed by needing to always be near a toilet
- Gender issues with health professionals – issues with discussing personal details with male doctors
- Lack of understanding of continence issues by health professionals, including wrong diagnosis

Quotes from the study are below.

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**“I feel sorry for those who are affected by this but [do] not come forward. If we explained it to the people, especially our people, because I feel that many women tend to talk and gossip about it, but if we address the problems to others, to make it easier for them not to feel shy to talk to their doctors. I know better now. If I was not too shy to talk to my doctor at the time this problem would have long gone and I would probably still be working by now.**

**That was why I left my job because of this problem”**

**28 year old Pacific Island Woman**

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<sup>26</sup> Lennan, M; Smallldridge, J and Fa’alau, F. *Urinary Incontinence: A Qualitative Approach*. Department of Women’s Health, South Auckland Health. 1999

**“Yeah, I’ve had lots of..... lots of doctors, you know like just [giving] prescriptions. Yeah and one just gave [me] one for paracetamol [when there for incontinence]. And I thought, gee, I must look like an idiot, being given headache pills for a leak.”**

47 year old Maori woman

**“No I wasn’t scared but as I said, embarrassed. He was a man doctor and I was not going to talk to him about that kind of problem and I think I went to Family Planning and talked to a lady doctor there.”**

56 year old Pacific Island woman

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## 6.3 Summary

There are issues with recognition of the issues from health professionals, service access, delivery, and equity. This is across all assessment, treatment and management, including product type and volume availability. For example bed wetting alarms for children can be accessed free in some areas, but require fundraising or private payment in most areas. Some people receive products to meet their leakage needs while others there is a mandatory issue of one product per day, irrelevant of need. People have to pay for their own after that. It is widely agreed that there should be increased funding for services and product e.g. diapers for children’s incontinence needs (over and above “normal” child diaper needs), bed wetting alarms, bowel irrigation equipment, pads etc.

There are no child specific incontinence services and this is known to not be best practice.

There are gaps and limited human resources in the areas of continence specialists and advisors as well as knowledgeable nursing, psychologist and social worker input.

## 7 Costs of Incontinence

### 7.1 Direct and Indirect Costs

Costs of incontinence include both direct and indirect costs, and costs to both the state and individuals (the incontinent person and their carers). Examples of both are in Table 7.

**Table 7: Examples of Direct and Indirect Costs**

Direct	Indirect
<ul style="list-style-type: none"> <li>— Assessment</li> <li>— Treatment</li> <li>— Products</li> <li>— Laundry</li> <li>— Medications</li> <li>— Surgery</li> <li>— Home care</li> <li>— Long term care</li> <li>— Avoidable admissions to hospitals</li> <li>— Longer hospital admissions</li> <li>— Skin inflammations</li> <li>— Urinary tract infections</li> <li>— Extra toilet paper and towels</li> <li>— Extra clothes</li> <li>— Cleaning – e.g. carpets, couches, mattresses</li> </ul>	<ul style="list-style-type: none"> <li>— Loss of wages</li> <li>— Loss of work days to employers<sup>27</sup></li> <li>— Loss of productivity – employees and voluntary work</li> <li>— Loss of leisure</li> <li>— Spouse and other family carer costs</li> </ul>

A 2006 study<sup>28</sup> in Australia estimates also that almost 60% of family carers who usually assist a person with managing their incontinence spent 40 hours or more actually carting for or supervising that person. This increase the loss of productivity and costs. The same study projects that by 2030 – 2031 the total expenditure for incontinence will increase by 201%, due to the ageing population. A similar expectation could be seen for New Zealand.

A New Zealand study<sup>29</sup> of older adults undergoing a support needs assessment found that residential care was recommended for 33.4%. It states:

*“For all of older age continence problems, mobility problems and dementia predicted residential care after assessment”.*

Additionally, a United Kingdom Department of Health fact sheet titled *“Good Practice in Continence Services”* states:

*“Incontinence is second only to dementia as an initiating factor for such moves [into residential care]”*

Table 8 takes the population of Australia and the total costs of continence there<sup>30</sup> (urinary only) and extrapolates this to an estimated New Zealand figure, based on New Zealand having approximately 20 percent of Australia’s population. This also assumes even costs in both countries.

<sup>27</sup> In Canada this is estimated to be 9 million work days per annum

<sup>28</sup> Australian Incontinence Data Analysis and Development. Australia Institute of Health and Welfare. March 2006

<sup>29</sup> Weatherall, M. Slow, T. and Wiltshire, K. Risk Factors for entry into residential care after a support needs assessment. The New Zealand Medical Journal 117 (1202), p U1075.

**Table 8: Costs of Urinary Continence – Australia and (estimated) New Zealand**

	<b>Australia</b>	<b>New Zealand (estimated)</b>
<b>Population</b>	20,000,000	4,000,000
<b>Annual cost (Treatment &amp; Personal)</b>	\$ 710,440,000 <sup>31</sup>	\$ 142,088,000

Even if costs between the countries are slightly different (i.e. the cost of workforce, each product) this still shows a very large government and societal cost.

One example of demand is from Australia. They have collated data from the Supplier Industry on the number of products being supplied to aged care residential people only. This numbers 149,487,277 in 2007 with an increase by 14,585,943 (9.7%) to 164,073,220 in 2008. It could be assumed the same or similar growth rate will exist in New Zealand.

## 7.2 Productivity Costs

A 2005 study<sup>32</sup> lists impacts of urinary continence (UI) in the workplace as:

“Of women with severe or very severe symptoms:

- 45% reported a negative impact on concentration
- 64% on physical activity
- 77% on self confidence
- 74% on completion of tasks
- 88% reported negative impact in at least one of the four areas above
- 4% indicated that UI had affected personal decisions about employment
- 2% changed the type of work they do
- 0.9 decreased the number of hours worked and
- 0.8 indicated they no longer work outside the home

A 2007 Canadian study concluded that the individual cost in a workplace was \$4,929 per person per annum. This was based on 1998 data so it is likely costs have increased. Productivity costs can include more frequent breaks, choosing to work from home, changing of jobs. Presenteesim is defined as:

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<sup>30</sup> Incontinence: A Canadian Perspective. Commissioned by the Canadian Continence Foundation (not dated)

<sup>31</sup> Incontinence: A Canadian Perspective. Commissioned by the Canadian Continence Foundation (not dated). Australian dollars

<sup>32</sup> Fultz N, Girsts T, Kinchen K, Nygaard I, Pohl G, Sternfield B. Prevalence, Management and Impact of Urinary Incontinence in the Workplace. Occupational Medicine 2205; 55: 552-557

“The problem of workers being on the job but, because of medical conditions, is not fully functioning..... an example of presenteesim might be an employee who suffers from depression and so is less able to work effectively. And another example might be the employee with a migraine headache who may have difficulty looking at a computer screen”<sup>33</sup>.

Based on the recent *Labour Force Participation Rate* by Statistics New Zealand<sup>34</sup> there are 2,181,000 employees in New Zealand. If the prevalence of 25% of women and 5% of men who are incontinent is simply averaged to be 15% (up to age 55 only) then that makes 327,150 employees with incontinence in the workforce. This number multiplied by \$4,929 makes a cost to the workplace in New Zealand of \$2,105,422,350.

A 2009 Canadian paper calls for the Government to increase funding for a range of interventions and promotion for incontinence and estimates a loss of 9 million work days per annum in Canada due to incontinence. A 2007 United Kingdom Clinical Review<sup>35</sup> reflects a range of studies on incontinence in the workplace. Pertinent to understanding the impact in the workplace are some of the research statements by individuals with incontinence. Some of these are replicated below and show the range of issues and employment types that can be affected.

Table 9: Individual’s Experiences

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**“Unfortunately my need for disposable diapers got out and everything went downhill. Construction workers aren’t the most easy-going bunch. I had lost the respect of the crews and therefore couldn’t do my job anymore. The owner called me in to his office and laid me off for lack of work in our busiest year”**

*Construction Worker*

**“Due to my work as a nurse I found my working life very much affected by my continence problems, which in turn contributed in my leaving the NHS. I now work in an office type environment and I have found it easier to accommodate my continence problems with regard to frequent visits to the toilet”**

*Nurse and now Office Manager*

**“I work in a “dirtyish” environment and it is difficult to find an opportunity to self-catheterise as frequently as I would like”**

*Engineer*

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<sup>33</sup> Medicinenet.com <http://www.medterms.com/script/main/art.asp?articlekey=40516>

<sup>34</sup>

[http://www.stats.govt.nz/browse\\_for\\_stats/work\\_income\\_and\\_spending/Employment/HouseholdLabourForceSurvey\\_HOTPMar09qtr/Commentary.aspx](http://www.stats.govt.nz/browse_for_stats/work_income_and_spending/Employment/HouseholdLabourForceSurvey_HOTPMar09qtr/Commentary.aspx)

<sup>35</sup> Evans, D. Continence Issues in the Workplace: A clinical review. *Continence UK*, 2007. Vol 1, No 2.

**“Going on airplanes is a nightmare. The toilets are far too small to get a wheelchair in and if it is a long flight, say to the USA, it is embarrassing to have to perform self- catheterisation behind a curtain into a jug, especially when travelling with colleagues from work”**

*Support Services Manager*

**“I was required to do occasional work on another farm seven miles away, which meant being away all day. This was difficult to cope with. I would find myself needing to change pads out in the field”**

*Farm Foreman*

**“It was difficult to leave a class in mid-lesson to go to the toilet. Colleagues used to complain about my classes waiting outside my locked room when I disappeared to use the toilet urgently between lessons”** *Unemployed science teacher*

## **8 Summary of International Approaches**

### **8.1 Australia**

The National Continence Management Strategy (NCMS) was established in 1998 by the Australian Government’s Department of Health and Ageing to provide funding to research and service development initiatives aimed at prevention and treatment of this significant problem. The purpose of the strategy was so Australians can live and participate in their communities with dignity and confidence. The developmental stage of the National Continence Management Strategy received initial funding of \$15.4 million over four years (Phase 1, 1998-2002). This phase had four major priorities:

- Public awareness, education and information
- Prevention and health promotion
- Quality of service
- Research

An additional \$16 million was approved in the 2002/03 Federal Budget for the continuation of the NCMS (Phase 2, 2003-2006). Phase 2 focused on the implementation and administration of existing projects and the establishment of further projects addressing prevention, community education and improved management of incontinence by primary health care providers, and within community care and residential aged care facilities.

In 2006 an additional \$18.2 million was provided to support the NCMS until 2010<sup>36</sup>.

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<sup>36</sup> <http://www.bladderbowel.gov.au/ncms/default.htm>

Funding for products is via both Federal and State funding, as well as through the Department of Veterans Affairs for war veterans. The Federal model provides for up to \$485 per year of products. This is changing 1 July 2010 to a payment to the individual of the \$485, so they can choose their own products. It is also estimated this will reduce government administration and transaction costs.

Most States and Territories have their own schemes as well, however the eligibility, arrangements and entitlements vary. There is also a Commonwealth funded Stoma Appliance Scheme for products for people with an ostomy.

Overall the system is fragmented with gaps and duplications becoming evident. There may be a move in the future to rationalize to one national scheme.

## 8.2 United Kingdom

A few years ago there was an agenda for change for incontinence services in the United Kingdom. This led to the development of Good Practice Guidelines and then National Guidelines<sup>37</sup>.

The availability of services and equipment from the health service vary from area to area. Some are free of charge, others require a prescription and others have to be privately purchased. Items can be prescribed by the GP or in some cases provided via the district nurse through continence services. The services are multi disciplinary and provide for relatively easy referral to other required disciplines.

Some areas have a waste collection service for disposable products.

## 8.3 Canada

The Canadian Continence Foundation has been very active over the years producing discussion, position and impact papers on incontinence for their government.

They are currently (as at May 2009) calling for their government to improve services and funding in the areas of:

1. Education of the medical community and public at large
2. Adding urinary incontinence to the Wait Times Strategy
3. Performing more cost effective surgical procedures for stress incontinence
4. Creation of community clinics
5. Access to conservative treatments such as physiotherapy and behavioural
6. Increased access to a choice of medications
7. Increased funding for absorbent products
8. Increased funding for catheters
9. Inequality in access to treatment between provides to be reduced

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<sup>37</sup> Department of Health. Good Practice in Continence Services. United Kingdom. Undated.

## 9 Recommendations

### **Recommendations: National Continence Policy and Plan**

To improve continence services and outcomes for New Zealanders it is recommended that the Minister:

1. Direct the Ministry of Health to develop, in partnership with the New Zealand Continence Association and the New Zealand Carers Alliance, a National Continence Policy and Action Plan to guide and coordinate investment, service improvement and provide for measurable outcomes
2. Direct the Ministry of Health to improve assessment and treatment for incontinence, and management (products) of incontinence
3. Direct the Ministry of Health to develop equitable access to incontinence services via consistent service delivery models, increased volumes and improved quality
4. Agrees that investment in educating more health professionals – both general health professionals (e.g. GPs, public health nurses, social workers) and dedicated incontinence specialist staff is a priority
5. Direct the Ministry of Health to carry out its commitments under the Carers Strategy Action Plan to improve learning for informal (family) carers so they can carry out their role more safely
6. Agrees to the need for more work on understanding the incontinence prevalence and needs of Maori and Pacific Island people in New Zealand

As a second tier priority:

7. Agrees to an increase in public awareness strategies
8. Direct the Ministry of Health to facilitate the development of a Best Practice Guideline, in partnership with the New Zealand Continence Association and the New Zealand Carers Alliance

## References and Useful Web Sites

Australia Institute of Health and Welfare. Australian Incontinence Data Analysis and Development. March 2006

British Medical Journal. Prevalence Rates for Constipation and faecal and urinary incontinence in childhood. Archives of Disease in Childhood. 2007. 92:486 – 489

Canadian Continence Association. Impacts of Incontinence in Canada. A Briefing Document for Policy Makers. May 2009

Continence Foundation of Australia. Position Paper: Toward an Equitable National Subsidy Scheme for Continence Products. November 2000.

Department of Health. Good Practice in Continence Services. United Kingdom. Undated

Evans, D. Continence Issues in the Workplace: A clinical review. Continence UK, 2007. Vol 1, No 2

Feng, W (MD, PhD) and Churchill, B (MD, FRCSC). Dysfunctional Elimination Syndrome in Children without Obvious Spinal Cord Diseases. Paediatric Clinics of North America. Vol 48, No 6, Dec 2001

Fultz N, Girsts T, Kinchen K, Nygaard I, Pohl G, Sternfield B. Prevalence, Management and Impact of Urinary Incontinence in the Workplace. Occupational Medicine 2205; 55: 552-557

Incontinence: A Canadian Perspective. Commissioned by the Canadian Continence Foundation (not dated)

International Organisation for Standardization. TC 173/SC 3 ISO Standards for Aids for Ostomy and Incontinence.

Johanson, J (M.D, M.S, F.A.C.G) and Lafferty, J (RN). American Journal of Gastroenterology. Vol 91, Issue 1, pg 33-26. June 2008

Lennan, M; Smallbridge, J and Fa'alau, F. Urinary Incontinence: A Qualitative Approach. Department of Women's Health, South Auckland Health. 1999

Lynch AC et al, The prevalence of faecal incontinence and constipation in a general New Zealand population. NZ Medical Journal 2001;114:474-7

Macmillan, A; Merrie, A; Marshall, R; and Parry, B. University of Auckland. June 2004

Ministry of Health. 2009 / 10 Operational Policy Framework. June 2009

Ministry of Health. "Who gets Disability Support Services and When do you pay?" July 1995

Ministry of Health and District Health Boards New Zealand. Continence Services Service Specification (Dom 104). 2001 and 2003

New Zealand Continence Association. Brief to Carers Alliance: Continence Services in New Zealand. 2008

New Zealand Continence Association. Consumer and Carer Panel Notes. 2008

Paediatric Society of New Zealand. Best Practice Evidence Based Guidelines Nocturnal Enuresis “Bedwetting”. 2005

Statistics, New Zealand. Census 2006

The Canadian Continence Foundation. Impacts of Incontinence, May 2009

The Economics of Incontinence. Committee 14. Consultant: Joseph Ouslander. Chapter 14, p 965 (not dated)

Thom D. Variation in estimates of urinary incontinence prevalence in the community: Effects of differences in definition, population characteristics, and study type. Journal American Geriatric Society. 1998; 46: pages 473-480

Tsang, B (Dr). Nocturnal Enuresis. New Zealand Doctor. February 2006, 17 – 21.

Wainwright T. South Island Shared Support Agency (Ltd) Source for defining incontinence: adapted from “A Review of the Need for and Current Organisation of Continence Services in Canterbury. August 2006.

Weatherall M. Numbers, costs and treatments for Urinary Incontinence in New Zealand. Draft NZCA Report. March 2009

Weatherall, M. Slow, T. and Wiltshire, K. Risk Factors for entry into residential care after a support needs assessment. The New Zealand Medical Journal 117 (1202), p U1075.

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[www.aboutincontinence.org/site/about-incontinence/prevalence/](http://www.aboutincontinence.org/site/about-incontinence/prevalence/)

[www.bladderbowel.gov.au/ncms/default.htm](http://www.bladderbowel.gov.au/ncms/default.htm)

[www.carers.net.nz](http://www.carers.net.nz)

[www.continence.org.au](http://www.continence.org.au)

[www.continence.org.nz](http://www.continence.org.nz)

[www.eric.org.uk](http://www.eric.org.uk)

[www.iso.org/iso/iso\\_catalogue](http://www.iso.org/iso/iso_catalogue)

[www.kea.org.nz](http://www.kea.org.nz)

[www.medterms.com/script/main/art.asp?articlekey=40516](http://www.medterms.com/script/main/art.asp?articlekey=40516)

[www.moh.govt.nz/moh.nsf/indexmh/dhbfundingperformance-nsf](http://www.moh.govt.nz/moh.nsf/indexmh/dhbfundingperformance-nsf)

[www.nzgg.org.nz](http://www.nzgg.org.nz)

[www.paediatrics.org.nz](http://www.paediatrics.org.nz)

[www.stats.govt.nz/browse\\_for\\_stats/work\\_income\\_and\\_spending/Employment/HouseholdLabourForceSurvey\\_HOTPMar09qtr/Commentary.aspx](http://www.stats.govt.nz/browse_for_stats/work_income_and_spending/Employment/HouseholdLabourForceSurvey_HOTPMar09qtr/Commentary.aspx)

## Appendix One Interviewees and those who Supplied Information

Andrea Lord (RN), Private Continence Nurse Advisor, and part of the early establishment of Nurse Maude continence services in Christchurch

Anne Bell, Disability Services, Ministry of Health, Wellington

Anne Foley, Health of Older People, Ministry of Health, Wellington

Barry Cahill, Chief Executive Officer, Continence Foundation Australia

Bobby Tsang (Dr), Specialist Pediatrician, Northshore Hospital

Cheryl Hammond, Continence Advisor Bay of Plenty DHB, and Executive Member of the NZCA

David Bratt (Dr), Principle Health Advisor, Work and Income

Doug Matthews (Social Worker), Canterbury DHB, also undertook a 2009 survey on DHBs and continence services

Fran Binnie (RN), Original Continence Advisor in New Zealand and Inaugural Member of the Continence Advisors Group in Auckland, Original Secretary for the NZCA

Frances Ryan, (RN) Public Health Nurse with expertise in Incontinence, Executive Member NZCA

Jan Zander, Executive Officer, NZCA

Jane Craven, Senior Advisor, Accountability Team, Performance Sector Accountability & Funding Directorate, Ministry of Health

Jane Harvey (RN), Continence Nurse and Advisor Urology Department, Burwood Hospital, was on the inaugural Otago Continence Advisors Group

Jean Hay-Smith (Dr), Senior Lecturer in Rehabilitation, Wellington School of Medicine and Health Sciences; Senior Lecturer in Women's Health, Dunedin School of Medicine University of Otago

Jill Brown (Physiotherapist) Waikato DHB and private advisor

Karl Moen, Federation of New Zealand Ostomy Societies

Laurie Hilsgen, Carers New Zealand, Executive member NZCA

Liz Cairns, Manager Serious Injury, ACC

Mark Weatherall (Dr), Consultant Geriatrician, Associate Professor, President NZCA

Maree Frost (Physiotherapist), NZCA Executive Member, Christchurch

Roger Harris (Dr), ex President of NZCA and geriatrician

Ted Arnold (Prof), Urologist Burwood Hospital, inaugural member of the Canterbury Continence Advisors Association and NZCA, organiser of training in New Zealand

Tor Wainwright, author of continence based paper and template for Canterbury DHB and South Island Shared Support Agency Ltd

Valerie Smith, Disability Services, Ministry of Health, Wellington

## Appendix Two Nationwide DHB Service Specification: Supply of Consumables

### APPENDIX 2

#### Supply of Consumables

All items are supplied at the discretion of the Specialist Continence Nurse, and are to be included in the consumable prescription.

Provision of consumables will usually be prescribed as per the guidelines given in the table below. These guidelines are a tool to assist decision making about the appropriate prescription of product based on need. There may be occasions when it is appropriate to prescribe more product than is indicated in the guidelines, or when it may be justifiable to prescribe products not included in the guidelines.

Product	Type	Range
Pads	350 ml capacity and up	1 - 4 per day
Uridomes		30 - 35 per month
Leg Bags	Standard Urocare	At least 2 per month 1 - 2 every 6 months
Night Bags	Standard Argyle, Incare, Simpla	1 per week 1 per 3 months
Net Pants		2 per 3 months
All-in-one briefs (nappies)		1-4 per day
Indwelling Catheter	Latex	1 every 2 weeks
Indwelling Catheter	Silicone or Hydrogel	1 - 2 every 3 months
Intermittent Catheters		4 - 10 per month
Gloves	Latex	100 – 200 every 3 months
Thigh Straps		1 every 3 months
Leg Straps		1 every 3 months
Skin Bond		1 -2 per month
Urihesive Strips		30 - 35 per month
Catheter Valves		at least 1 per month