Caring for the Carers – *He Atawhai i te Hunga Ngākau Oha o Aotearoa*

The New Zealand

Carers' Strategy and Five-year Action Plan 2008

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Foreword from the Minister for Social Development and Employment

When I talk about the importance to New Zealand of social investment to strengthen families young and old, I am not talking about intangible ideas. I am talking about how Government can support real people, every day, to help build an inclusive and vibrant nation.

Carers are a key part of this. Their extraordinary work may not often generate headlines, but it does make a crucial difference to the quality of life of those around them. By voluntarily devoting their own time to support the sick, frail, disabled or vulnerable they transform the lives of others. Carers are among the unsung heroes of kiwi life.

During consultation a mother who had cared intensively for her disabled daughter for 20 years told of how her only regret was that she had been unable to provide the kind of opportunities for all her children that she had always dreamed of. Like her, there are many people – sons, daughters, parents, friends or neighbours who unquestioningly forgo their own choices and opportunities to help others. While many do this without hesitation, we can do much more to support and recognise carers’ vital contribution to society and to the economy and ensure they continue to have choices and opportunities available to them.

I was delighted when the New Zealand Carers Alliance asked Government to lead a Strategy in partnership with them. The feedback from carers and the general public has helped us to develop a vision for carers and priorities for immediate action. The vision is where New Zealand Aotearoa is a society that values individuals, families, whānau or aiga who support others who need help with their everyday living.

This Strategy is something in which we all have an interest. All of us may be a carer or need the support of someone close to us in the future. The Government has shown its commitment and the Five-year Action Plan sets out clearly the actions we will take to support the vision.

Government alone cannot address what is necessary to make the vision happen. I now call upon all other parts of society to help us achieve the vision of this Strategy. This much needed change can only happen when we all work together to make this a country where we care for the carers.

I would like to thank the individuals and groups who have contributed to this Strategy, in particular the Carers Alliance and my Ministerial colleagues. The efficient development of this Strategy illustrates the commitment of all those involved.

Carers should be proud of what they do, and New Zealand should be proud of its carers. This Strategy is the first step to giving carers a real voice and we will continue to listen to that voice in the years to come.

Hon Ruth Dyson
Minister for Social Development and Employment

Introduction

Introduction

> "There is the need for a concerted effort to simplify, demystify and redirect the delivery mechanisms for support given to carers and those they care for, so that principles of empowerment and choice, and goals of simplification, flexibility and innovation, are the drivers of systems and processes in the future."
>
> **Submission by a carer, September 2007**

In April 2007 Hon Ruth Dyson, Minister for Disability Issues and Minister for Senior Citizens, announced the development of a New Zealand Carers' Strategy (Carers' Strategy).

The Carers' Strategy is part of a wider Government process to improve the choices of parents and other informal carers so they can better balance their paid work, their caring responsibilities and other aspects of their lives.

Carers need to be properly recognised and supported in their caring role so every New Zealander can have choice and opportunities, in a society that respects and values them.

Who is a Carer?

A carer is anyone who supports a person with ill health, a disability, mental illness, an addiction, or in their old age. A carer's effort, understanding and compassion enables these people to live with dignity and to participate more fully in society.

Anyone can find themselves caring for another person, usually a family, whānau or aiga member, at any time. Often this can happen unexpectedly, eg as the result of an accident or sudden illness. Most carers see themselves not as carers, but as relatives or close friends of the person who needs support.

The Carers' Strategy focuses on carers who provide informal support for someone close to them: it may be a child, a spouse, a wider family, whānau or aiga member, a friend or a neighbour. Carers help where people cannot manage the tasks involved in everyday living without help and support.

Carers come from all walks of life and vary in age, ethnicity, culture, characteristics and outlooks. What they have in common is a shared belief in helping others to have a good quality of life.

Why New Zealand needs a Carers' Strategy

> "New Zealand is relying on its family carers as never before, and for families to meet this challenge, those in caring situations must be supported, recognised and protected from the sometimes adverse consequences of having to care too much."

Submission by Carers New Zealand and the New Zealand Carers Alliance, September 2007

A Carers' Strategy is an investment for the future. Several social, economic and health indicators show growing numbers of New Zealanders will need care in the following decades. As a society we will want people to be able and willing to provide care.

It is the right time for informal carers to become visible and for their needs to be recognised and supported.

Ageing population

Like other OECD countries, New Zealand has a rapidly ageing population. By the late 2020s it is estimated there will be more than one million New Zealanders aged 65 years and over, compared with half a million in 2006. Improvements in health mean that many older people are living longer and healthier lives. As the population ages the number of people over 85, who are more likely to have a disability and need support, and the number of people supporting others will increase.

Medical advances

Advances in medicine mean younger people with high support needs are surviving and living longer. As well, younger people with complex impairments, eg autism, are being diagnosed earlier. These young people want to be a part of their communities and will need support for a long time to help them participate as much as they can.

Skills shortage

New Zealand is facing a very real skills shortage with employers finding it difficult to recruit staff for certain positions. Creating more opportunities for people to balance paid employment and caring benefits individuals and their families as well as strengthening the New Zealand economy, enabling us to compete in the global marketplace.

Informal carers contribute to the economy, but some of them find it difficult to stay in paid work because it is hard to balance a paying job with their caring role. Helping and supporting carers who want to work, move into and stay in formal employment, or participate in training will mutually benefit the carers, employers and the economy. It is giving carers the same choices as other New Zealanders.

Lack of support for carers

The New Zealand Disability Strategy formally recognises the needs of carers. The Strategy's Objective 15 is to value families, whanāu and people providing ongoing support. Despite this, a number of policies and laws in New Zealand affect carers but few focus on the carers themselves. Although the interests of carers and the people they support are closely related, policies and assistance are more likely to be directed towards the person needing the support first, with little specific consideration given to the people giving the support and their families.

This lack of support often means informal carers have fewer opportunities than people without caring responsibilities to participate in education, work, and social and community activities.

Carer contribution undervalued

Informal carers often feel their caring work is undervalued and they don't receive the support and recognition they deserve for their contribution to New Zealand society, especially in the economic and health sectors.

Scope of the Strategy

Who the Strategy covers

The New Zealand Carers' Strategy is for carers and their families.

At the time of the 2006 Census approximately 420,000 New Zealanders reported providing support for an individual with ill health or a disability within the previous four weeks.

Approximately 47% of carers are supporting someone outside their household, 38% are helping someone inside their household, and 15% are supporting people inside and outside the carer's home. Sometimes a number of people assist a person who needs support.

What the Strategy does

This Carers' Strategy outlines the Government's vision for carers in New Zealand. It provides a framework of principles to guide policy development and the delivery of services by government agencies and Non Government Organisations (NGOs) that work with carers.

The Strategy helps identify what actions are needed to ensure carers are supported, valued and recognised for their important role in caring for other people in New Zealand society. This important role includes supporting others with:

- personal care, eg dressing, toileting and bathing
- physical movement and therapy, eg getting them out of bed, exercising and transporting them
- keeping them safe, eg in the home
- practical household tasks, eg cooking and housework
- administrative tasks, eg paying bills and arranging appointments
- emotional support, such as encouraging and reassuring, spiritual support and advocacy.

This support could be in the home, in the workplace, in educational settings, or at social activities.

Delivering the Strategy

This Strategy is a living strategy. It is accompanied by an Action Plan that details how the Strategy will be brought to life within its first five years. The Action Plan will be the dynamic part of the Strategy and regularly updated over time.

Ownership

To be successful the vision and objectives of the Strategy need to be owned by all New Zealanders.

Central and Local Government, NGOs, health and disability providers, businesses and communities all need to work together. By doing so they can ensure the needs of carers and their families, whānau or aiga are catered for in their activities and considered in their decision-making.

Government agencies will consider the Carers' Strategy in their service delivery and in any other activity that affects carers, to ensure carers' views are taken into account.

Carers and their families need to take ownership of the Strategy to make sure it continues to look after their priorities over time. Carers need to make sure their voices are heard as the Strategy and Action Plan progress.

Leadership and Governance of the Strategy

The Strategy has been developed by a collaborative partnership between the Carers Alliance (a network of 45 NGOs) and the Government. This relationship will continue. A Carers' Strategy Governance Group, including representatives from the Carers Alliance, will oversee the Strategy. This group will make sure progress is being made and that the Strategy remains relevant to carers over time.

The New Zealand Carers' Strategy

Vision

> "What would help carers feel more recognised and valued... empowering carers by treating them as equals with different knowledge; and listening and acting respectfully."
>
> Submission by a carer, August 2007

The key to the New Zealand Carers' Strategy is its vision for New Zealand carers. This vision has come from talking to carers and the people they deal with. It is the ultimate goal the Strategy will work towards achieving.

The government's vision for carers in New Zealand is that:

New Zealand Aotearoa is a society that values individuals, families, whānau or aiga who support others who need help with their everyday living.

This will be achieved when:

- carers have choices and opportunities to participate in family life, social activities, employment and education
- carers' voices are heard in decision-making that affects them.

Caring should be something people do with pride and feel supported when they do it.

By valuing and supporting New Zealand carers, we help to develop strong healthy families that are able to help their members reach their full potential as participating members of society.

By improving choices for carers in employment and education, we help to address skill shortages within the economy, to improve productivity levels and to help carers to secure their present and future income and resources for retirement.

Guiding principles

The Carers' Strategy has four guiding principles to help achieve its vision for New Zealand carers.

These principles will be used by government agencies to ensure the perspectives and needs of carers, their families and those close to them are considered and catered for in any activities and decision-making that affects carers. NGOs, businesses and community groups can use these principles as well, in their work with carers and those close to them.

The Strategy's four guiding principles are:

- Recognise diversity
- Be proactive
- Enable carers
- Be inclusive.

> “Sensitivity to the culture, stage of life, impairment and life expectancy by those designing and assessing the care arrangements is necessary rather than a ‘one style of caring fits all’ approach.”

Submission by NZ Spinal Trust, September 2007

> “Carers often know what they don’t want to happen, but don’t know what other alternatives or options are available.”

Submission by a carer, September 2007

Recognise diversity

Carers exist throughout New Zealand society and vary in age, ethnicity, culture, characteristics, outlooks and needs. Actions taken under the Carers’ Strategy need to recognise and acknowledge the diversity of carers’ needs and aspirations to be effective. Actions need to:

- value and respect carers, the people they support and their families in terms of their cultural identity
- consider the needs of specific groups, eg young carers and Māori and Pacific carers
- acknowledge the changing and differing needs of people at different ages and at different life stages, including the key points where life changes are occurring
- be conveyed in a way that recognises carers’ differing needs for, and ability to access, information
- be flexible and not overly rule-driven, meaning they are able to respond to individual circumstances for carers and those close to them.

Be proactive

Carers need to know support is available for them when they need it. Support mechanisms need to be:

- responsive, eg information is available when carers need it and support services are put in place quickly
- easily accessible
- available to carers so they can plan ahead and prepare, rather than live from day to day.

> "Autonomy… goes beyond the principle of empowerment. Autonomy allows each individual to choose their own most positive supports. Having chosen these supports, individuals gain strength from connecting and participating in wider groupings of family/whānau and communities on the basis of independence."

Submission by the Mental Health Commission, September 2007

> "The life choices of carers and those they support are integral to each other. Evidence shows disabled people's quality of life correlates to having people in their lives that are close to them, care for them, and love them."

Submission by CCS Disability Action, September 2007

Enable carers

Carers need to have choices and the freedom to develop and maintain their personal, family, whānau or aiga and community support systems. Any action taken as part of the Carers' Strategy needs to reinforce the carer's ability to tap into these support systems. Formal support systems need to be reliable and to provide real support to carers.

Be inclusive

It is important to acknowledge that the needs of carers, family, whānau or aiga and the person being supported are often intertwined and, for some, the formal support system is a key part of their lives.

It is also important to recognise that both the carer and the person they support have rights as well as needs and, at times, these may not be the same. The impact of policies and decision-making on the entire family, whānau or aiga unit needs to be considered as well as the impact on the person being supported.

Objectives of the Strategy

The priorities identified from feedback during the Carers' Strategy's consultation process have been used to identify five areas for action. These areas are central to the Strategy and are the areas where Government will work to bring New Zealand closer to its vision for carers.

The five objectives of the Carers' Strategy are:

- provide information
- protect the health and wellbeing of carers
- enable carers to take a break
- provide financial support for carers
- provide training and pathways to employment for carers.

Measuring the success of the Strategy

> "My experience is no one is responsible for ensuring anything happens... It is crucial this Strategy has tangible measurable outcomes and is sufficiently resourced."

Submission by a carer, September 2007

To make sure the Carers' Strategy is doing its job successfully and moving us towards its vision for carers in New Zealand, the Government will:

- monitor the progress of the implementation of the Strategy
- readjust the Strategy's objectives to adapt to changing circumstances
- be accountable to carers and their families for delivering what the Strategy says it will deliver in the Five-year Action Plan.

A key part of keeping the Strategy vibrant and effective is a partnership of commitment to the Strategy between government and stakeholders. These stakeholders, along with government, will have a role in achieving the vision of this Strategy and include:

- carers
- families, whānau, aiga or circles of friends of carers
- people receiving support
- the community and voluntary sector, including NGOs and advocacy organisations
- funders
- employers, unions and other workplace organisations
- crown entities, eg ACC and District Health Boards
- the wider public.

The role of monitoring, research and evaluation

International and local research on caring combined with what carers said during the consultation period has given the Government a solid understanding of the major issues for carers and a better knowledge of what has been done elsewhere to support them. A programme of monitoring, research and evaluation will help to build this knowledge as the Strategy is implemented.

The Government will develop a monitoring framework to measure the progress of the Strategy and Five-year Action Plan. Monitoring, research and evaluation will be key ways of keeping carers and other stakeholders up to date with how well the Strategy is doing for New Zealand carers.

The New Zealand Carers' Strategy monitoring, research and evaluation programme will:

- provide information to help the Government develop the Strategy over time as more is learnt about the current and future needs of carers
- help the Government to understand the Strategy's progress towards achieving its vision for carers, as the Action Plan is put into place.

The New Zealand Carers' Strategy monitoring, research and evaluation programme will include:

- ongoing programme monitoring against Action Plan objectives and an annual report on progress
- using existing information and research to investigate the characteristics of carers and the nature and type of problems they face.

The First Five-year Action Plan

Joint Chief Executives' Foreword

The Government has laid out a vision for carers and this Action Plan provides specific detail on how it will take steps forward in the next five years to deliver that vision. We are committed to ensuring a whole-of-government collaborative approach is taken to supporting carers. This will involve working in partnership with carers' organisations, business leaders and other key stakeholders.

This Five-year Action Plan will ensure the Strategy makes progress towards achieving the vision. It describes what our agencies will do for carers, by when and by whom. The Plan forms a key part of the government's wider action plan to improve people's Choices for Living, Caring and Working.

It is based on the priorities identified by carers as part of an extensive consultation process. The initiatives extend across the continuum of carers' needs. They include health and wellbeing, opportunities to take a break from caring, learning for caring, financial support, training and pathways to employment, combining work and care, and information provision. The actions will build on and align with the progress already made by other strategies, such as the Disability Strategy and the Positive Ageing Strategy.

This Action Plan is the first step towards achieving the vision. There will be ongoing action plans to ensure that the Strategy continues to represent the priorities of carers and the Government.

The programme of work in the Action Plan presents us with exciting challenges. It will require our agencies to work together with a wide range of organisations and individuals. We are confident that the energy, innovation and professionalism of our staff will ensure that we continue to make a positive difference in the lives of New Zealand carers.

Peter Hughes
Chief Executive
Ministry of Social Development

Stephen McKernan
Director General
Ministry of Health

Christopher Blake
Secretary
Department of Labour

Dr Jan White
Chief Executive
Accident Compensation Corporation

Introduction

> "The only way the vision and principles will meet our needs is if they are supported by actions."
>
> Submission by carer, August 2007

The New Zealand Carers' Strategy Five-year Action Plan (the Five-year Action Plan) is what the Government will do in the next five years to address what carers see as the key issues for them.

This Action Plan is the first step towards achieving the Strategy's long-term vision for carers that:

New Zealand Aotearoa is a society that values individuals, families, whānau or aiga who support others who need help with their everyday living.

This will be achieved when:

- carers have choices and opportunities to participate in family, whānau or aiga life, social activities, employment and education
- carers' voices are heard in decision-making that affects them.

The five objectives of the New Zealand Carers' Strategy that the Five-year Action Plan aims to address are:

- Provide information
- Protect the health and wellbeing of carers
- Enable carers to take a break
- Provide financial support for carers
- Provide training and pathways to employment for carers.

The actions identified in the plan will aim to address these key areas and bring this Strategy to life for carers, their families, whānau or aiga and those close to them by providing better support for them in their caring roles.

The challenge to NGOs, employers, unions and communities is to also consider ways they can address these issues in their own decision-making and activities, as they work with carers and their families.

What follows is a list of the Carers' Strategy objectives with the actions various Government Agencies will take to address them for New Zealand carers.

1 Provide information

ACTION ONE

Scope a national specialist carer centre to develop information products, such as a national respite locator and a generic carer information pack

This action will include:

- scoping potential for a national specialist carer centre to enhance and build the capacity of the existing ways carers receive information, advice and support. As part of this the centre could:
  - develop and promote a national respite locator and associated support directories (available online and in printed material). This would let families know where there are available beds, what they cost, and how they can access them
  - develop a generic carer information pack which would be relevant across different age groups and across diverse cultural groups. This will make sure all carers are aware of information and options available to them, eg employment information and career information, advice and guidance.

WHO IS RESPONSIBLE: Ministry of Social Development

WHO BENEFITS: All carers and the people they support. Government, Crown Entities, employers, unions, community groups and individuals will also have more access to information on caring.

TIMEFRAME: 2008.

2 Protect the health and wellbeing of carers

ACTION ONE

ACC will work across Government to develop a wellbeing and learning programme for informal carers

This action will include:

- pooling learning resources across Government to create access to learning about caring for all informal carers, regardless of who the funder is
- providing a range of learning opportunities on caring including face-to-face, online and paper-based training so carers can access learning at the start of caring, at transition points and through ongoing refresher courses
- developing resources for training in core skills and injury prevention.

WHO IS RESPONSIBLE: ACC

WHO BENEFITS: All carers and the people they support. Carers' skills and ability to undertake their role will improve from the learning.

TIMEFRAME: Initial information and training in place by June 2008.

ACTION TWO

Update informal carers' training requirements

This action will update contractual requirements for informal carer training programmes with consideration of carers' preferences and needs raised in consultation on the Carers' Strategy.

WHO IS RESPONSIBLE: Ministry of Health

WHO BENEFITS: Informal carers of Ministry of Health clients with long-term physical, sensory and intellectual disabilities who are generally under the age of 65 years.

TIMEFRAME: Training contracts will be updated from 2009 as new contracts are agreed.

ACTION THREE

Improve mechanisms for providing informal carers of people with mental illness or addiction with supports in the health sector through revised specifications for those services

This action will include:

- considering improvements to the mechanisms for providing supports to carers who are families, whānau, aiga or friends of people accessing mental health and addiction services through a review of service specifications for those services
- a focus on the range and types of supports available for families of children with a mental illness.

WHO IS RESPONSIBLE: Ministry of Health

WHO BENEFITS: Informal carers of people with serious mental illness or addiction.

TIMEFRAME: 2008–2009 with the revised service specifications becoming part of accountability arrangements with District Health Boards on 1 July 2009.

3 Enable carers to take a break

ACTION ONE

Increase the flexibility and reliability of respite care for informal carers

This action will include:

- investigating what changes can be made to the Carer Support Subsidy for respite care to improve its fairness for carers regardless of their financial circumstances
- enhancements to the Carer Support Subsidy that can be adopted by individual funders within current financial parameters
- identifying additional ways of improving respite care provision as part of a 2008 review of respite care options currently funded through Vote Health.

WHO IS RESPONSIBLE: Ministry of Health

WHO BENEFITS: The 2008 review of respite care options will benefit a wide variety of carers of older people, people with serious mental illness, addiction or chronic health conditions, and children, young people and adults with disabilities or complex health conditions. The actions on the Carer Support Subsidy will look to benefit carers who have trouble accessing respite care due to their financial circumstances.

TIMEFRAME: 2008–2010.

ACTION TWO

Increase age-appropriate residential respite services for disabled people with high needs

This action will include implementing a plan to increase access to residential respite services by:

- seeking additional respite beds in Northland, Bay of Plenty, Waikato, Hawke's Bay, Wellington, Nelson-Marlborough, Canterbury and Southland regions by December 2008
- considering the need for additional respite beds in other areas by September 2009.

WHO IS RESPONSIBLE: Ministry of Health

WHO BENEFITS: Informal carers of people with long-term physical, sensory or intellectual disabilities or a combination of these, who are generally under 65 years and accessing services from the Ministry of Health.

TIMEFRAME: By December 2008 and September 2009.

ACTION THREE

Provide additional assistance with recruiting relief carers

This action will include identifying the unmet need for, and planning the additional purchase of, assistance and advice for carers who need to recruit relief carers.

WHO IS RESPONSIBLE: Ministry of Health

WHO BENEFITS: Informal carers of people with long-term physical, sensory or intellectual disabilities or a combination of these, who are generally under 65 and accessing services from the Ministry of Health.

TIMEFRAME: 2008–2009.

4 Provide financial support for carers

ACTION ONE

Improve income support provision for families with high and complex needs

This action will include:

- examining options for allowing a wider group of people with significant caring responsibilities the choice of accessing income support
- examining options to improve the assessment process for determining eligibility to income support for carers.

WHO IS RESPONSIBLE: Ministry of Social Development

WHO BENEFITS: Informal carers who support people with high and complex needs.

TIMEFRAME: 2008–2010.

ACTION TWO

Develop a proposal for a Carers Allowance

This action will develop a proposal for a Carers Allowance payment, similar to the Child Disability Allowance, to be made available to some informal carers of adults to acknowledge their caring role.

WHO IS RESPONSIBLE: Ministry of Social Development

WHO BENEFITS: Informal carers of adults who currently receive no assistance with the costs of care.

TIMEFRAME: 2008–2011.

ACTION THREE

Work to better understand the cumulative effect of means-testing on work incentives for households

This action will include work to better understand the combined effect of different means-tests by Government on work incentives for carers.

WHO IS RESPONSIBLE: Ministry of Social Development

WHO BENEFITS: Informal carers who are feeling the impacts of a combination of different means-tests on their ability to earn.

TIMEFRAME: 2008–2012.

5 Provide training and pathways to employment for carers

ACTION ONE

Encourage and support employers to recognise carers' skills and needs

This action will include making the business case for recognising the needs of carers in the workplace, and recognising the needs of carers when developing information and tools targeted at employers. We will build on existing initiatives to encourage employers to:

- recognise the skills of carers when hiring staff
- provide flexible working arrangements for carers.

WHO IS RESPONSIBLE: Department of Labour

WHO BENEFITS: Informal carers who are finding it difficult to balance their employment with their caring role. Employers who may be able to retain experienced and skilled workers.

TIMEFRAME: 2008–2009.

ACTION TWO

Investigate ways to support carers into employment

This action includes exploring:

- introducing additional carers leave, either paid or unpaid
- removing any barriers including financial barriers to employers hiring carers, such as additional costs incurred in providing additional leave
- the potential scope, objectives and outcomes of a project to improve the support and services available to carers to support their transition into, and continued participation in, paid employment.

WHO IS RESPONSIBLE: Department of Labour

WHO BENEFITS: Informal carers who find it difficult to balance their employment with their caring role, and employers who want to keep experienced and skilled workers who may otherwise leave the formal workforce because of the demands of their informal caring roles.

TIMEFRAME: 2008–2010.

ACTION THREE

Investigate ways to improve recognition of prior learning and skills acquired while caring

This action will include a feasibility study to look at ways to improve systems for recognising prior learning and skills acquired while caring, including those gained through the carer learning initiative, in order to help carers participate and achieve in tertiary education and/or enter paid employment. The Department of Labour will work with other Agencies on this study and report in 2010.

WHO IS RESPONSIBLE: The Department of Labour

WHO BENEFITS: Any carers who want to have the skills they use, learn and develop as informal carers formally recognised.

TIMEFRAME: 2008–2010.

Appendices

Appendix 1:

Developing the Carers' Strategy

Background to caring in New Zealand

In nineteenth century New Zealand, outside of hospitals, charitable aid institutions and asylums, the needs of most disabled people were met by the informal sector, eg churches and families, and mutual self-help organisations such as Friendly Societies.

By the end of the century, Government was providing grants or subsidies to charitable organisations for some groups such as the Jubilee Institute for the Blind (now known as the Royal New Zealand Foundation of the Blind).

In the first half of the twentieth century, with better diagnosis and in some cases better treatments, large psychiatric institutions replaced asylums, and later specialised psychopaedic hospitals for children with intellectual disabilities were set up. Specialised care in large institutions was one of the main care options for some groups of disabled people.

From the 1950s, smaller community-based institutions and care became common. This is when the IHC set up day-care centres and residential homes for people with intellectual disabilities.

By the early 1970s, there was a strong move to enable people with disabilities to stay with their families by providing access to the supports they needed to live in their communities. The Disabled Persons Community Welfare Act 1975 symbolised this.

Since the 1980s, people who need support, and their carers, have found it more complex to access services. There is a wider range of support available, but many developments have been poorly co-ordinated and people have had to meet specific criteria to get the support they need. Increasingly, they have had to negotiate support and help across a range of government and voluntary agencies.

In April 2007, the Government announced it wanted to improve the choices for and quality of life of informal carers and those close to them by developing a Carers' Strategy. With the number of New Zealanders needing support expected to grow significantly, especially as our population ages, there will be a greater demand for family, whānau and aiga members to take on those caring roles. A Carers' Strategy that recognises, values and supports carers in real terms is an investment for New Zealand's future.

The Carers' Strategy consultation process

The New Zealand Carers' Strategy has been informed by the voices of carers, the people they support and the organisations that work with them every day.

To ensure carers' voices were heard in the development of the Strategy, the Government formed a partnership with the New Zealand Carers Alliance, a network of 45 NGOs who represent carers throughout the country. A consultation process ran over an eight-week period from Monday 23 July to Friday 14 September 2007.

A consultation document, called Caring for New Zealand Carers, was distributed during this consultation period. The document outlined a draft vision, guiding principles and ideas for areas where changes needed to be made, and asked people to respond to these.

The document was distributed to 1,000 individuals and organisations, made available on the internet, and promoted by government agencies and the Carers Alliance. Carers New Zealand produced a summary of the document in the Family Care magazine of which 23,000 copies were distributed to carers and other interested people. The consultation was also publicised in a number of Government Agency and NGO newsletters including Carers New Zealand's e-zine, which is sent monthly to 14,000 people. There was a good response to the consultation process.

Two hundred written submissions were received and over 1,000 people attended a number of public meetings held over the consultation period. In addition the New Zealand Carers Alliance received over 600 responses to a short survey asking carers to identify their priorities for change. The survey was available at meetings and on the Carers New Zealand's website.

Working closely in partnership, the Carers Alliance and representatives from a number of Government Agencies spoke with and listened to carers, read their submissions and reviewed the research, evidence and policies for carers in other countries.

The wide consultation process has ensured that carers, people who need support, families, whānau or aiga, community groups, NGOs and Government Agencies who work with carers and their families have all had the opportunity to contribute to the development of the Strategy.

Appendix 2:

What we know about New Zealand Carers

Thirty-eight percent of carers in New Zealand are between 45 and 64 years old, with a further 31% between the ages of 30 and 44 years. Twelve percent of carers are 65 years or older.

The most common source of help for those being supported is from a family, whānau or aiga member. Help with household tasks, such as heavy housework and meal preparation, was most commonly given by a spouse or partner, followed by daughters, sons and parents. After family and whānau, the next most frequent sources of help were paid individuals and voluntary organisations.

Women are more likely to be carers than men. Around 63% of carers in New Zealand are women. International research shows women are also more likely to be the main carers and to provide assistance for more hours.

Māori and Pacific peoples are more likely to provide unpaid support than other ethnic groups. Generally, Māori and Pacific peoples face complex caring responsibilities, particularly in the 15–44 years age group. The younger average age of Māori and Pacific carers, their higher rates of severe disability, and their larger households make it more likely they are caring for more than one person and across more than one generation.

Many New Zealand carers identify themselves as unemployed and may be interested in paid employment if suitable jobs are available. Around 73% of people aged 25–64 years who provided unpaid support to a sick or disabled person outside their household in the previous four weeks at the time of the 2001 Census were also in paid employment. Around two-thirds of these people were employed full-time.

Appendix 3:

Stakeholders

Every New Zealander must take ownership of the Carers' Strategy if it is going to work effectively for carers and those close to them. The stakeholder groups that will play leading roles in making the Strategy work are:

- ***Carers*** – This Strategy has been developed for carers. Their lives will be directly affected by the outcomes from the Strategy so they need to take ownership of it. They need to tell us what is working, what is not, and what we can do better.
- ***Families**, **whānau, aiga or circles of friends of carers*** – These will benefit directly from the family-focused support provided by the Strategy. Families play a vital role – they have the most direct relationship with the carer and the person being supported and often help with the caring role.
- ***People receiving support*** – The relationship between the support a carer receives, and the support available to the person they care for, is intertwined. It is important to recognise both the carer and the person they support have rights as well as needs and at times these may not be the same. If the carer is supported

properly in their role, it can remove stress from the caring relationship and they can better care for those people who need their support.

- ***The community and voluntary sector, including NGOs and advocacy organisations*** – These groups are often the advocates for carers. In their advocacy role they can support carers and the Government to work together to keep the Strategy alive and current. They can also use the Strategy to guide their own decision-making.
- ***Funders*** – Funders can ensure that funding and funding policies reflect the vision, principles and objectives of the Strategy and that workplace practices consider the needs of the person being supported, the carers and their families. These groups play a vital role in making sure work towards achieving the vision outlined in the Strategy can continue.
- ***Employers, unions, businesses and other workplace organisations*** – These groups can use the Strategy to create workplaces that recognise and consider the needs of carers and their families. This approach will ultimately benefit both employers and carers. Employers may at any time be or become carers and potentially will benefit from the Strategy in their caring role.
- ***Crown Entities, eg ACC and District Health Boards*** – Crown Entities can use the Strategy to guide their policy development, decision making and service delivery. They can use the Strategy to help ensure that the needs of both the person who has ill health or is disabled and those close to them are considered in service delivery and supports.
- ***Government*** – Government can use the Strategy to guide its policy development and decision-making. This will ensure future decisions have considered the needs of carers and will work towards achieving the Strategy's vision for carers in New Zealand. Government has a responsibility to keep listening to carers so their voices continue to be heard.
- ***The wider public*** – Every New Zealander can work to achieve the vision outlined in this Strategy by recognising and valuing carers in their communities and by supporting them when they need it. Many New Zealanders will become carers sometime during their lives and they may need the same support.

MINISTRY OF SOCIAL DEVELOPMENT
Te Manatū Whakahiato Ora

CARERS
ALLIANCE

New Zealand Government