



RESPITE IN NEW ZEALAND

WE MUST DO BETTER

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PURPOSE

To drive action, and not just discussion.

This paper sets out ideas and actions to develop a fairer and more sustainable respite system for New Zealand.

It was commissioned by the New Zealand Carers Alliance in association with Alzheimers NZ and IHC.

Many parts of our respite system are broken and need fixing. Respite exists in a suite of associated services, which may influence the need for respite services. This suite of services is not addressed here. The paper also does not dwell on the problems with

respite, which are well documented and acknowledged elsewhere. The paper is about action, and what is needed now to support improvement.

The paper is purposefully brief and to the point. The problems with respite exist across multiple sectors, but dementia is a key focus in this paper due to the immediate and growing need in our country.

Our aim is to promote an informed debate that will lead to action and improvement.

ACKNOWLEDGEMENTS

Synergia would like to thank the people and organisations who contributed their time, energy and insight into the development of this paper. Special thanks to those who contributed the real stories that have been used as the basis for the two case studies included in this paper.

* Sam and Felicity's stories are based on real examples and combine elements and themes from a range of situations that carers experience in New Zealand.

ACTION SUMMARY

Effective change needs to occur across the system to fix our respite services. Figure 1 shows the actions required across providers, funders and commissioners, policy makers, as well as carers and the people they care for.

For carers and the people that they care for, it is about making sure that the system meets their needs and they have suitable options available. We know Carers' Support is not working and its replacement with flexible budgets that people can use for what they need, when they need it, should be rapidly expanded.

For providers, a quality and outcomes framework will provide benchmarks to

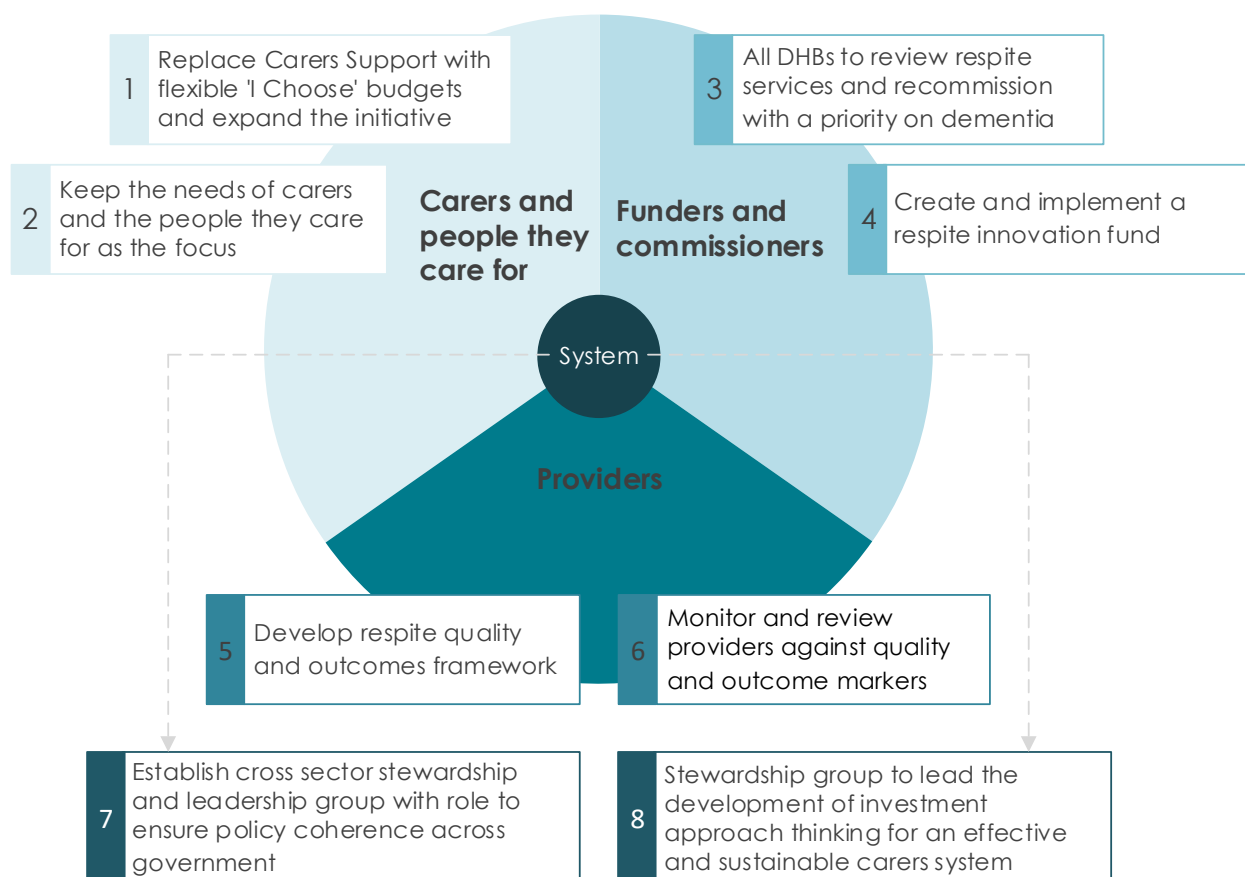
support service improvement and allow for innovation across the country.

How respite services are funded and commissioned need to be reviewed by DHBs to meet the needs of their populations, with an initial focus on dementia. Creation of a respite innovation fund will create the space necessary for providers to be able improve respite services.

Leading all this needs to be a cross-sector stewardship group creating coherent policy for the country. They also need to drive an investment approach to ensure the respite system is effective and sustainable.

These actions are explained further on pages 14 and 15.

Figure 1: Actions for respite services



Every year New Zealanders provide an estimated **\$7 billion to \$17 billion** of unpaid care.

Imagine if everyone stopped providing this care. Imagine the massive **financial and social impacts** for the country.

SAM'S STORY*

My wife was diagnosed with dementia a decade ago aged 71. I care for her 24/7. Continuing to care for my wife is important. The lack of support and services is making it more and more difficult.

My wife was diagnosed with dementia 11 years ago at the age of 71. She was able to continue work as a free-lance editor for 3 years but over the years, things have changed. She soon became unable to help with simple household chores but was still able to enjoy poetry and discussions about politics like she always did. Now, she can only read short excerpts from the newspaper and needs help dressing herself.



I care for my wife 24/7.

I've had very little support. Like most carers I'm over 80 and have developed health issues of my own. I'm in constant pain which makes the constant work of caring very difficult. More recently walking has become difficult and painful, so I get about on crutches.

When you love someone, you care for them. You look after them for the sake of human decency, but you can't do it alone. Especially when you have your own health issues. It's hard enough and I get very little support. Most carers are over 80 and have health issues themselves. This makes it difficult for people to look after my wife, so I can have a break.

There is no regular respite where I live. Our GP, social workers and nurse assessor all tell me that I MUST have 2 weeks of respite

every 6 to 8 weeks. We were allocated 91 days of respite by the nurse assessor, and I was told to look on Eldernet. There I found there was no regular respite service in our DHB. The allocation was misleading and disheartening – what is the point in having access to 91 days of respite when there are no services?

When all else fails, every health worker tells me to use my "carer support". The carers reimbursement is still the same as it was 22 years ago. Employing a carer costs between \$25 - \$50 per hour so any support is expensive, and many people can't afford this. I've been told I need to send my wife to a rest home. I have tried this before and it didn't work. She wants to be at home in a familiar environment, and I want to care for her. I just need some help from time to time.

What would help is:

- An appropriate carers' allowance that is tagged to inflation
- Substitute Carers who are well-trained and capable of supporting people in their own homes and in the community. Many carers are brilliant but need appropriate training to better support people.
- Rest homes operate not only on a medical model but also take into account social, emotional and psychological needs of the person.
- Finally, I know they mean well but it would be great if GPs, social workers and nurses stopped telling carers "make sure you look after yourself- because if you don't you will get really sick and most likely die" To be able to look after myself, I need good quality, suitable respite services available in my area.

WHO ARE CARERS AND WHAT IS RESPITE?

Over 400,000 people identified as carers in the Census. Multiple agencies fund respite services.

Most New Zealanders care for someone at some point in their lives, whether that be a new-born, an elderly parent, or someone with a disability.

Sometimes the level of care provided goes over and above what is considered 'normal' and places considerable and, at times, unmanageable expectations on carers.

This level of care changes relationships. It causes stress, loneliness, lost income, and lost sleep. At times, carers are unable to focus on themselves and suffer the physical, mental, and social consequences. Carers in these circumstances need respite.

Respite¹ is the chance for the carer and person being cared for to take a proper break.

Effective respite is about what works for the caring triad of the person, carer, and whānau.

Respite can involve extra support provided at home or a person moving away from home for a brief period. Respite helps the carer 'recharge' and go again. It also gives the person being cared for a break from their carer.

Respite services exist for the disability, mental health, health of older people, dementia and palliative care sectors.

The significant funders of respite services are the Ministry of Health (MoH) via health of older people, Disability Support Services (DSS) and the Accident Compensation Corporation (ACC).

There are some consistent needs and some unique issues across conditions and situations needing respite. However, no matter the condition or situation, a respite service must provide a break to the carer, the person being cared for, and offer some therapeutic benefit.

Respite care keeps families together, keeps people out of hospital, reduces the use of funded services, delays the degeneration of people's physical and mental wellbeing and is, at its core, a cost effective and societally just investment.

One study calculated that every \$1 spent on services to support carers gives a \$4 return; another study showed this return to be \$8 for every dollar spent.²

¹ Respite terms are used interchangeably. These terms include respite, short break, carers support, holiday, rest and time out.

² Association of Directors of Adult Social Services. (2015). Economic Case for Local Investment in Carer Support.

The numbers

Carers

In the 2013 census, 430,000 New Zealanders identified as carers. This is equivalent to 10% of the population. As a population, carers are older and earn less than the general population. Each week, an average carer provides 24 – 36 hours of support. This is estimated to be \$7.3b - \$17.6b worth of care³. For comparison, the total health budget is \$16.1 billion.

Of all these carers, 31%-61% of New Zealand respite users are able to use their full respite allocations⁴.

In 2016 over 18,000 received the Carer Support Subsidy from Disability Support Services (DSS) with another 3000 receiving a respite service.⁵

Who are they looking after?

There are approximately 1.1 million people living with disabilities in New Zealand. A survey found that 33% of disabled adults in private homes in New Zealand needed regular assistance for personal or domestic tasks. Family members are likely to be the main providers of support, and for caregivers of disabled children, 10% were found to have an unmet need for domestic support because of their child's impairment⁶.

New Zealand's population is getting older. In 2013, New Zealand's population aged

over 65 was almost 630,300⁷. This is set to increase to 1.5 million by 2046, with 320,000 over 85 year olds⁸.

The number of people living with dementia is also increasing, meaning more people will need extra care, and be unable to provide care to anyone else.

An estimated 62,000 people were living with dementia in 2016, an increase of 29% over 5 years. By 2050, the prevalence of dementia is expected to increase to 170,212 people in New Zealand.⁹

Who funds what?

Respite services are funded through:

- District Health Boards for health of older people, mental health and long term chronic conditions
- MoH for DSS
- ACC for carers who support people who have had an accident

Contracts may be long-term or short-term depending on the situation. A Needs Assessment and Service Co-ordination (NASC) service assesses entitlements. These services are run by different organisations for different DHBs and for different conditions. Respite funding may come from a different funding stream to other funded care people receive.

³ Association of Directors of Adult Social Services. (2015). Economic Case for Local Investment in Carer Support.

⁴ Ministry of Health. 2017. Disability Respite Survey 2016: Summary of responses. Wellington: Ministry of Health.

⁵ Ministry of Health. 2017. Demographic Report on Clients Allocated the Ministry of Health's Disability Support Services: As at September 2016. Wellington: Ministry of Health.

⁶ Stats NZ (2017) Supporting Disabled People: 2013

⁷ Statistics NZ. (2018). *NZ.Stat Table Viewer - 2013 Census*.

⁸ Stats NZ. (2016). National Population Projections: 2016(base) - 2068 - Media Release.

⁹ Deloitte (2017). Dementia Economic Impact Report 2016. New Zealand: Alzheimers New Zealand.

WHAT'S BROKEN THAT NEEDS FIXING

Respite helps people continue caring and supports carers to live good lives themselves. However, the system is not working for many people. Carers and respite providers have told us about some of the problems that need fixing.

Carers aren't receiving the support they need

Carers across New Zealand do an amazing job. They go above and beyond what is normal and often put the needs of those they care for ahead of their own. Carers are not being sufficiently supported in their caring role. This is leading to carer breakdown and situations where people can't cope anymore. Respite is one critical area where we can support carers. However, services are currently not meeting people's needs, not universally available and not adequate.

Carer Support Subsidy

The Carer Support Subsidy is an area of respite that has not been working for some time. The Ministry of Health is in the process of replacing it within Disability Support Services with a new flexible respite budget called 'I Choose'. This is a great step forward but needs to be made available to more carers, not just those caring for people eligible for disability support services. Also, the level of carer support or flexible funding is grossly inadequate and inequitable, with one carer stating that "in today's world this might buy me 2 or 3 hours of support, when I care for my son 24/7 – and I don't get the Subsidy every day. This amount has not changed for many years and at \$73 for 24 hours is often not a viable option for purchasing respite".

Service availability

Carers are saying that quality day or short break residential services are not readily available for the people who need them. Either the services are not available (especially in rural areas), or do not have the capacity or capability to provide quality services. One carer stated that whilst he received an allocation for respite, when he explored his options, no providers in his area would deliver services into his home and required him to travel. He could not travel so the allocation went unused.

This is not just due to funding, but due to DHB priorities and focus. Some DHBs and other regional funders are not investing in the respite services they should be, leading to inequalities across the country. It is difficult for services to be sustainable, especially for small providers, and even more difficult to innovate to provide quality services because of the lack of impetus from DHBS.

Service quality

For the services that do exist, there is limited quality assurance and monitoring. In some cases, poor quality services can cause people's health and wellbeing to deteriorate. This deterioration can negate any benefit for the carer, as well as the person requiring support and means that the service is not a respite service, as a respite service must provide therapeutic benefit to the person being cared for.

Service sustainability

Provider organisations say that respite is not a very attractive service to deliver. The fragmented nature of current policy, and procurement and compliance requirements affect their ability to innovate to better meet the needs of the community. Pockets of excellence do exist in parts of the country. Often these innovations are not being widely adopted. Services, sometimes due to competitive forces, exist in siloes and are unable to connect and share innovations.

Funding framework

Funding for respite services is delivered across many different areas, such as health of older people, disability, palliative care, mental health, and ACC. This fragmented funding environment often involves multiple organisations and government agencies, creating duplication and confusion. Respite services are not organised around people but around funding. The current setup forces people to work around the system instead of the system working for them.

Policy coherence

One potential reason for fragmented funding is the policy environment. There are policies and strategies for mental health, health of older people and carers. The strategies are reasonable in isolation, but together they do not form a coherent system, and work needs to be done to ensure cohesive policy across sectors and across the country. There are overlapping actions and priorities, leading to duplication, waste and ultimately a suite of services that don't meet people's needs. Streamlined policy settings will help to improve the system and reduce waste.

Investment thinking

Supporting carers to continue in their caring role is a sound investment. However, there is a lack of investment thinking within policy and funding organisations. The implications of not investing are that caring situations become unmanageable, they breakdown and, as a result, emergency arrangements are needed. These arrangements often come with high costs and with poor outcomes for the carer and the person being cared for.

Carer centred solutions

What carers tell us is that there is no real understanding of the needs of carers and the people they care for to inform the strategies that are developed and the services that are commissioned. One interviewee said that respite is not people centred, but funding centred. Commissioning organisations need to better understand the needs of carers in their local communities and co-design services accordingly.

Leadership

With multiple funders and a fragmented policy environment, clear leadership is required to ensure national consistency. This does not currently exist for the respite system. New Zealand needs national leadership that can provide cohesive policies that work across sectors for people and for providers. Without national leadership, any effort is likely to be ineffective or short term when we need real, sustained change to address the problems we currently face, and prevent them from getting worse.

*The carers' support subsidy is totally **inadequate.***

*I effectively get **\$9.50 an hour.** This was reasonable 22 years ago, but nowadays it's lower than the minimum wage.*

WHY WE NEED TO INVEST IN RESPITE

We must not underestimate the value that carers provide to the person, families/whānau and communities.

People not receiving respite when they need it is having a significant impact on the daily lives of New Zealanders, and on unnecessary hospital and crisis response costs.

The problem will get worse if we don't act. More and more people are living with dementia, for example. The population is ageing, and our services are not prepared. We know that when caring situations break down, the costs can be significant for urgent response services.

The annual health budget is \$15.6 billion, social security and welfare is \$30.6 billion and education \$14.1 billion. The value of care provided by informal carers is estimated to be between \$7 billion and \$17 billion. This equates to 3-8% of GDP. Informal carers provide huge amounts of value to New Zealand through their caring role and their contribution needs to be recognised. Any other initiative or programme that saved the country as much as informal carers do would be looked after, supported and invested in.

Each week, informal carers in New Zealand spend an average of 24-36 hours caring for someone.

We need to change this conversation away from seeing respite as a cost, to seeing it as an area to invest in. We invest

in education to ensure New Zealand has the skills to be productive and competitive. We need to invest in respite to ensure carers are able to carry out their role without excess stress.

Investing in people to continue in their often-unpaid carer role benefits them and New Zealand. Investment does not always mean money. It means acknowledgement, information, and access to support if needed. It means recognition that caring for someone with needs that are over and above what others determine to be normal can, at times, place unmanageable expectations on carers. It also means thinking deeper about the consequences of not investing and seeing the implications over time.

Some think an investment approach only applies to younger people and that the benefits from investing can only be realised years later. It is our view that an investment approach applies to everyone at all stages of life and that well thought through investments can realise benefits in the short, medium and longer term for all ages and populations.

Respite services should be developed to ensure that carers are supported and receive the help they need to continue caring.

*Funders need to **review** current arrangements and develop a plan to **recommission** respite services.*

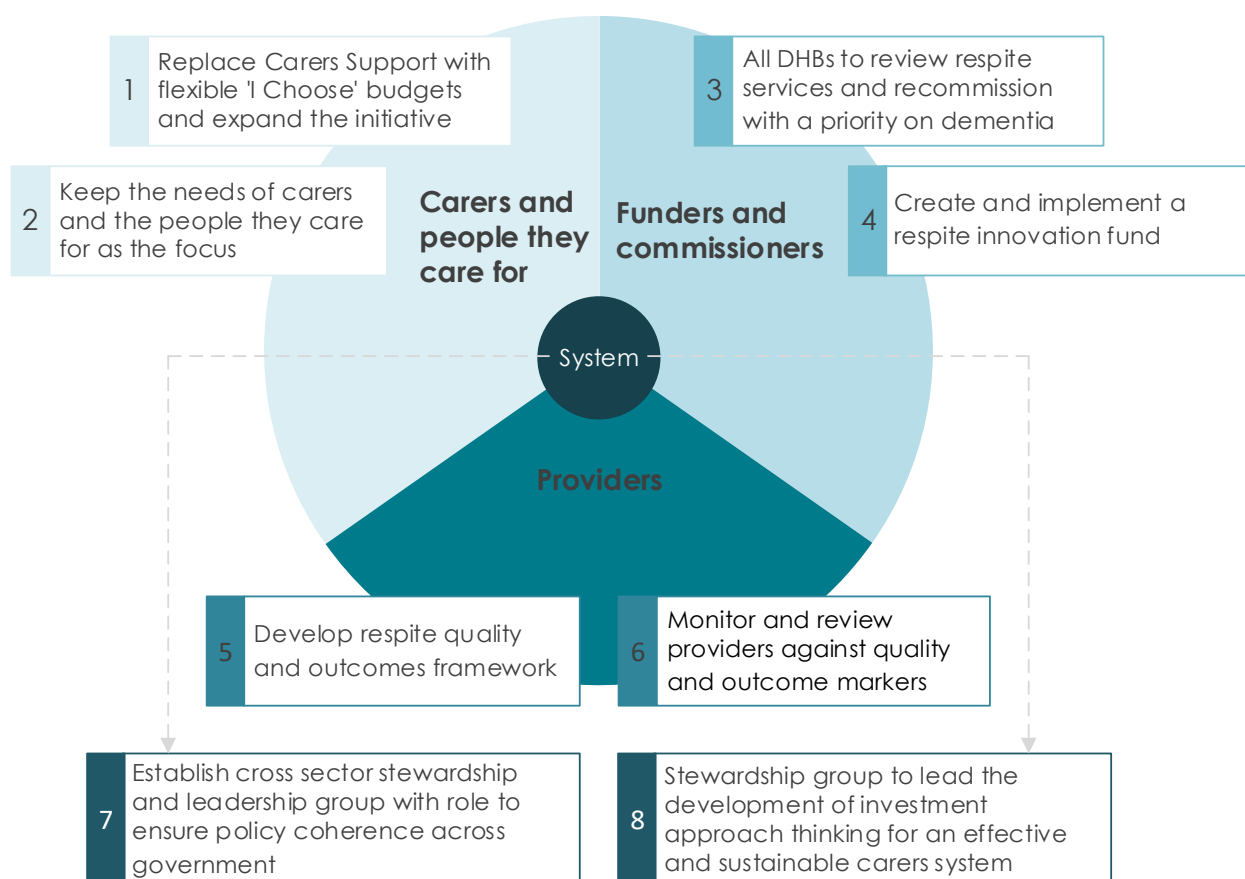
*It doesn't need to be complex, everyone knows the issues, it just **needs to happen.***

ACTION IS NEEDED TO IMPROVE THE SYSTEM

We need to think about, and create, a coherent carer system, which has relevance across conditions, funders and locations. Effective respite is a key part of this system.

We have organised our ideas around four areas: (1) carers and people they care for, (2) funders and commissioners, (3) providers and (4) the system of respite. We are proposing eight core actions to improve respite services, described below.

Figure 1: Actions for respite services



1. Replace Carer Support with flexible 'I Choose' budgets and expand the initiative

The MoH needs to continue to roll out the I Choose model which is set to replace the Carer Support Subsidy in

disability. The MoH should implement this important person-directed initiative across all other funded areas of respite care, including health of older people, mental health and palliative care.

2. Keep the needs of carers and the people they care for as the focus

The carers and the people they care for need to be the focus of efforts for respite. While the needs of providers are also important, a service is not a good service unless it works for the people who need it.

3. All DHBs to review respite services and recommission with a priority on dementia

DHBs are one of the main funders (via the MoH) and commissioners of respite services. They have a responsibility to meet the needs of their populations. It is true that many DHBs are under considerable financial pressure, with many exploring options to reduce demand for their services, better support people in the community, and reduce length of stay in expensive hospital settings. The evidence for investing in carers to support many DHB initiatives is strong.

As such all DHBs should review current respite arrangements and develop plans to recommission respite services that better meet the needs of their populations and be more nationally consistent. This will involve decommissioning some services. A suggestion is to start with respite services for carers of people with dementia as this is an area which is significantly lacking and not working for the New Zealanders who need it.

4. Create and implement a respite innovation fund

The MoH should explore the injection of innovation funding to support providers to prototype new respite options as part of the immediate recommissioning of services – it is suggested that the

pool be \$5million per annum be allocated. This fund should be allocated through DHBs and managed through an application process. The innovation funding would be time limited and enable providers and funders to trial new approaches to respite, evaluate their effectiveness and share learnings.

5. Develop a respite quality and outcomes framework

The MoH should work with other government agencies and providers to develop a quality and outcomes framework for respite services. The framework must cover all aspects of carer wellbeing including their experience of the available services. The framework will be used as a cornerstone for ensuring providers develop and deliver high quality services that people want and need.

6. Monitor and review providers against quality and outcome framework

Reconfigure provider quality assurance and compliance reporting to align with what the quality and outcomes framework. Use the framework to support sector-wide continuous improvement to make the system work for providers and those who rely on their services. By focussing on what really matters for people (quality and outcomes) we also aim to significantly reduce the compliance burden for providers.

7. Establish cross-sector stewardship and leadership group with role to ensure policy coherence across government

Co-ordinated, cross-sector action is needed to improve respite. The current fragmented leadership makes it difficult to drive co-ordinated and coherent action across the system. The MoH should establish a cross-sector stewardship and leadership group tasked with taking the actions in this paper and co-ordinating a system-wide response across the country. The group would be responsible for reporting to Minister/s on progress on improving the respite system and how the totality of government funding is being used to support improved outcomes for carers and the people they care for, not just the different silos of funding.

8. Stewardship group to lead the development of investment approach thinking for an effective and sustainable carers system

An initial area of activity for the stewardship and leadership group should be to develop guidance for funders and commissioners on taking an investment approach for respite for all ages and populations. This needs to provide the rationale for the

approach, the detailed economic evidence to support an investment approach and practical guidance on how to target investment in respite and carers.

Start here....

The respite system is in crisis. We must take action now. We suggest the following three actions be prioritised for immediate action:

1. All DHBs to review respite services and recommission, with a priority on dementia.
2. Develop a respite quality and outcomes framework.
3. Establish a cross-sector stewardship and leadership group with its primary role being to ensure policy coherence across government.

These three actions can be started immediately and will kickstart the changes that are needed to improve the respite system.

FELICITY'S STORY*

As parents do, we have cared for Michael since he was born. From when he was very young, we knew something wasn't quite right. Now he is a grown man and caring for him is what we do. But it's hard. We haven't had much in the way of support and it wears you out.

Our son Michael is 36 years old and was diagnosed with an intellectual disability at 4 years old. At first, we were strangely relieved. It answered a lot of questions. It gave us a reason for his behaviour and meant we could access support. When he was young this support really helped and met our needs. As he got older, and as he got bigger, we needed more and more support. Instead, we got less and less.

Michael is now a grown man. He has lots of very challenging behaviour. He hits out at people; doesn't understand his own strength; and he doesn't like to leave the house. We have struggled to find support workers who will come into our house, so we can have a break. My husband and I haven't had a holiday for 10 years.

The last time we went on holiday, it was such a disaster. Michael was staying in a residential care facility, but he didn't settle. We spent most of our time on the phone, trying to sort it out. In the end, we lasted one night and had to pack up and come home. We love our son, but everyone needs a break sometimes.

We get an allocation from the NASC but hardly ever use it. Appropriate respite services don't exist, and so we can't use our allocation.

It's just not worth the hassle organising something that we know is not going to work for Michael or for us.

My health is not great, I can't work, and my social network is incredibly small. Not being able to work has placed financial pressure on our family and pressure on my husband as the sole income earner.

What we really need is someone who can



take the time to build a rapport with Michael. Someone we can call on every now and again to help us out. Even just so we can go to the movies or for a walk. The providers we have used in the past can't seem to hold onto staff long enough and just as someone is getting to know Michael they move on and we start all over again.

I'm not sure what we are going to do over the next few years. My husband and I are getting older, and our health is getting worse. I fear what things will be like when I'm 70, which is not that far away.

We want the best for our son and for ourselves, but we are not getting the support we need to achieve that.

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