



Removing Disabling Experiences:

a vision for the future of our people



SUPPORTING INDEPENDENT LEGAL THINKING.

Warren Forster Wellington, April 2022

An independent research report produced with generous support from the **New Zealand Law Foundation Te Manatū a Ture o Aotearoa** through its *International Research Fellowship Te Karahipi Rangahau ā Taiao*.

Cover image: Anna Menendez, TruStock.

Dedication and Acknowledgements

This work is dedicated to the people of Aotearoa New Zealand. I would like to start with acknowledging the generations of our people who have lived with disabling experiences. Thousands of you have shared your stories with me, answered surveys about your vision of the future, and met with me over the course of this research. I have had the privilege of representing, supporting, and meeting many of you in my practice in the law.

The past decade has seen people coming together on a journey of change. We have galvanised support around doing things differently. This report calls for us to now embark on the next part of that journey. It calls for leadership. It calls for things to be done differently. Most of us will live with impairment at some point in our lives. We can redesign our systems for helping each other and remove the disabling experiences from our lives.

I would like to acknowledge those who have shaped these ideas. The visionary Sir Owen Woodhouse who wanted to develop a single system but, in the end, had to put this aside for one day in the future. Those who kept these ideas alive and ensured they were not forgotten including Sir Kenneth Keith and Sir Geoffrey Palmer, and Sir Michael Cullen who almost got there in 1990.

To the inspirational women who challenged me to think about solving these problems. My mother Mrs Val Forster whose experiences in 2005 started my journey. Dr Denise Powell for her tireless work with Acclaim Otago Inc for nearly two decades and her endless enthusiasm for change. Miriam Dean QC who reviewed our research and put it on the Government agenda. Hon Nikki Kaye who as Minister took it seriously and along with her colleagues put the processes in train to bring about change. Associate Professor Brigit Mirfin-Veitch who challenged me to finalise this work, and Dr Huhana Hickey for taking the time to review this and write a foreword. I would also like to acknowledge the members of the 52nd and 53rd Parliament who spent time discussing these ideas.

Today when we talk about the future of the ACC system, some people still say that until ACC sorts itself out we cannot start expanding it. To them I say that expansion to a single system will remove many of the problems that have plagued the ACC system for decades. It will remove the discrimination, the disputes about whether the impairment was caused by accident or not, the delays, and the negative experiences. For too long, fear of setting precedents or raising levies have stymied calls for change.

DEDICATION & ACKNOWLEDGMENTS

Whenever calls for expanding the ACC system are raised, people in power acknowledge there is a gap and this causes discrimination, but rather than do something about this, they put it aside for a day in the future and acknowledge that it is a debate we need to have. In my view, and in the view of the thousands of people I have talked to, we can't keep pushing this aside. We've been doing that for decades. We need to have this debate now. One of the aims of this work is to spark this debate.

I acknowledge those who call for a royal commission, or some other inquiry to look at the past problems with, or the future direction of, the ACC system. To me, the way forward is clear. We don't need another five-year delay, because we can have the future system in place in that time. We need to work together, and we need action.

I would like to thank the numerous international academics, non-government organisations and governments who have met with me along the way. You opened your doors and shared your experiences and ideas with me. I would particularly like to acknowledge the help from Professor Gerard Quinn, who hosted me at Raoul Wallenberg Institute at the University of Lund in Sweden and introduced me to the many people who were interested in developing these ideas further.

To Lynda Hagen, Executive Director of the New Zealand Law Foundation, her team and the Board of Trustees, for all of their patience, support and encouragement over the past nine years to bring together a body of work in relation to disability, including the ACC system, access to justice and accessibility. This support has had a profound impact on our society and will continue long into the future.

Finally, I'd like to thank my family for sharing so many adventures with me, your patience, and for the support you have given me. I wouldn't be here today, and this work would not have been done if it wasn't for you. It takes a lot to rethink the future of systems of law, but this work is for you and all the other families that make up our communities and our society. Together, we can change peoples' experiences.

Warren Forster, Wellington, 10 August 2022

FOREWORD

Foreword

It is not often one is invited to write a foreword, and I am honoured to do so for this report. Not only as this subject matter is an interest of mine in an academic, legal and personal sense, but also as a disabled person who has the lived experience of inequity of the delivery of services given to disabled people dependent on the cause of their impairment. I have had the pleasure of knowing Warren Forster for a number of years now and have seen him work to try and find better outcomes for disabled people and reduce the disparities experienced through the existing systems. These systems have created inequities between those who have “accident” cover and those who do not.

In 1967, Sir Owen Woodhouse was commissioned to develop an insurance scheme for people who acquire a disability to have fair and equal access to income support, care, and treatment. It began with people who had accidents, which established the Accident Compensation Corporation (ACC). However, before the next intended stage of including non-accident disability, a change of government meant the next phase didn't go ahead. Over the decades since its implementation, ACC has had multiple changes made to it, but none that completed the original intentions of the Woodhouse Report. This has led to crisis situations in the disability sector, and as outlined in this report “Unless we act now, the current imperfect and unfair system will continue to be written into the stories of our children's children and their children. The decisions that are made in the next decade will shape the experience of generations of future New Zealanders.”

In writing this report, Forster has provided a detailed analysis after 50 years of the ACC system, making recommendations to take our system and transform it so it works for all of us and is equitable, sustainable and future protected.

Current models for disability outside of the ACC model have become increasingly unsustainable over the decades. Even Enabling Good Lives, a new disability service model, will not be sustainable without reforms to its funding regimes, and it provides no integration with income support, employment and healthcare which are essential to inclusion in society. Unless there is a major reform in providing integration between income support, care and treatment in disability, the unsustainability of this system will reach crisis level soon. This is already evident for those who have neurodiverse and mental health issues by the lack of accessible housing and respite and care services available to them.

For too long we have accepted the disparities around causation of disability, which has led to those with a medically “caused” diagnosis, despite it being no fault of their own, missing out on resources due to not qualifying for accident cover through ACC. There has also, over time and with amended changes in the law, been increasing disparities in ACC on who can and can't get support. Forster's review highlights these disparities and how they have created a fault-based system despite its claims of being a no-fault system. Someone who is born blind for example, does not claim ACC nor can they, yet another person who becomes blind through an accident, receives the resources and supports to rehabilitate, and in many cases is reintegrate back into society and work and has access to housing.

FOREWORD

Yet neither party is to blame for their disabilities, and while one gets support and assistance, the other is left to find the help they need themselves.

Forster outlines plans to reduce these disparities and inequities and provides a roadmap for a streamlined system that is consistent with, and expands on, the original Woodhouse Report. What was not in existence at the time the Woodhouse Report was written, namely the UN Conventions on the Rights of Persons with Disabilities (UNCRPD), the Rights of the Child (UNCROC) and the UN Declaration on the Rights of Indigenous Peoples (UNDRIP), which the New Zealand Government has signed up to, now provide the basis for updating the vision and purpose by incorporating the international principles espoused by these, and including the principles of our own Te Tiriti o Waitangi to this, to ensure that full equity without discrimination is implemented if this report is adopted.

While the original Woodhouse Report and subsequent policies in place have excluded certain impairments, an all-inclusive system can provide more integrative and responsive policies where clients have their needs met and funded. This would also reduce any duplication in the provision and funding of these services, saving money for the Government by streamlining services and providing a more sustainable practice where providers aren't having to deny services to one group and yet providing them to another group. While I remain sceptical of insurance as the scheme to do this, we do need to be able to fund this, and ensure it is viable for long-term care and treatment and is not just a short-term answer.

This is the first report I have read in decades that has given a serious review of the original report and applied the principles as originally intended into this, with a new lens and a new approach. I do believe it can be a way forward if it can successfully reduce the disparities, the inequities and provide a single system for all facing their impairments/disabilities. Forster's report is one to be proud of and to take heed of. We finally have a clear and detailed approach on how we can transform our system and bring it up to date, while also addressing the funding issues which have long been the elephant in the room. I do hope we have an opportunity to finally see the Woodhouse vision fully implemented, but with a modern lens addressing the rights of marginalised people, cost, and inequities.

To our political leaders, recognise that this is not your area of expertise and take heed of those in the sector who are providing the expertise for the leaders to then implement. Until we see disabled in Parliament representing disability, we need our leaders to open the door and not shut it further.

Finally, I want to send a wero (challenge) to the disability community, this includes, whānau, allies, providers and all those involved in our world. Instead of fighting each other, arguing over impairments and funding, we need to put our own egos aside and come together for the bigger picture, which is a better and more inclusive world for all.

Dr Huhana Hickey MNZM, MInstD, Auckland, 7 August 2022

CONTENTS

TABLE OF CONTENTS

BACKGROUND TO THIS REPORT	1
A VISION FOR THE FUTURE	3
Basis for this Vision	3
Guiding Principles of Design.....	3
Realising this Vision.....	4
CHAPTER 1: THE CURRENT CONTEXT	5
WHERE ARE WE AND HOW DID WE GET HERE?	5
What is the problem that needs addressing?	5
Disabling experiences of everyday New Zealanders	5
CORE CONCEPTS FOR REALISING VISION	9
The importance of Te Tiriti o Waitangi	9
The Convention on the Rights of Persons with Disabilities.....	10
Impairment must be inclusive of all impairment	11
A COORDINATED SYSTEM FOR REMOVING DISABLING EXPERIENCES	12
Disabling experiences.....	12
System of enforceable rights	13
System for Accessibility	13
System for Non-Discrimination.....	14
PEOPLE WANT THE GOVERNMENT TO CREATE A SINGLE SYSTEM.....	14
People agree with the vision	15
A single integrated system will bring benefits for our people with impairments	15
A single integrated system will bring benefits to us all.....	15
People want the Government to act.....	15
WHAT NEEDS TO BE DONE SO WE CAN MOVE FORWARD?	16
CHAPTER 2: THE FUTURE SYSTEM	17
THE FOUR ENFORCEABLE RIGHTS OF THE FUTURE SYSTEM.....	17
The enforceable right to personalised social supports.....	17
The enforceable right to income support.....	18
The enforceable right to healthcare.....	19
The enforceable right to habilitation.....	20
Adding additional enforceable rights	20
GUIDING PRINCIPLES FOR EXPANSION.....	21
Expansion Principle 1: Te Tiriti and Human Rights compliant by design.....	21
What obligations exist on the Government?	22
Recommendation for Principle 1: Te Tiriti and Human Rights Compliant.....	23
Expansion Principle 2: Create integrated person directed service and person-centred dispute resolution services	23
What is meant by Integration?	23

CONTENTS

Person directed service	24
Person-centric dispute resolution system (non-adversarial first steps)	25
Integration of health, social, financial & habilitation outcomes	26
Recommendation for Principle 2: Person-directed integrated system with person-centred dispute resolution	26
Expansion Principle 3: Innovate the funding model	27
What is meant by funding model?	27
Why is innovation in funding necessary?.....	27
Recommended innovation is to develop a perpetual sovereign wealth fund.....	28
Removing the outstanding claims liability from the ACC system.....	29
Introduce a levy to increase the size of the wealth fund	30
Other funding options	30
Recommendations for Principle 3: innovate the funding model.....	31
Expansion Principle 4: Progressive Realisation	31
By impairment or person specific characteristics.....	32
One enforceable right at a time	32
Individual choice or employer choice.....	32
A rights-based social investment approach	33
When the economic conditions meet certain criteria	33
What progressive realisation might look like.....	33
Recommendations for Principle 4: Planned Progressive Realisation.....	33
Expansion Principle 5: Healthier and Safer Communities.....	33
No-fault and the return of fault	34
Investing in communities to improve health and safety	35
Recommendations for Principle 5: Healthier and Safer Communities.....	35
Expansion Principle 6: Coordination with accessibility and discrimination prevention systems	35
Recommendations for Principle 6: Coordination with systems to remove disabling experiences	37
List of all principles and recommendations.....	37
Principle 1: Te Tiriti and Human Rights Compliant.....	37
Principle 2: Person-directed integrated system with person-centred dispute resolution	38
Principle 3: innovate the funding model.....	38
Principle 4: Planned Progressive Realisation	39
Principle 5: Healthier and Safer Communities	39
Principle 6: Coordination with systems to remove disabling experiences	39
CHAPTER 3: GETTING FROM HERE TO THERE	40
HOW WE MOVE FORWARD TOGETHER	40
DEVELOP THE FRAMEWORK.....	40
Task the Ministry for Disabled People to start the policy work for expansion (Year 1).....	40
Build relationships with stakeholders (Year 1).....	41
Build the economic models to collect funds for the future system (Years 1-2)	41
Sovereign wealth fund	41
Additional funding mechanisms	42
Develop the economic and legislative infrastructure to allow these models to be used	42

CONTENTS

The alternative to the innovation of funding	42
Build the data systems (Years 1 – 2)	43
Build capacity (Years 1 – 10)	43
Debate and plan the expansion roadmap (Years 2-4)	43
By impairment or person specific characteristics.....	44
By type of enforceable right (personalised social supports, income support, habilitation and healthcare).....	46
Individual choice or employer choice	46
A rights-based social investment approach	47
When the economic conditions meet certain criteria	47
Determine policy settings (Year 2 – 4).....	47
Policy Settings for Health.....	48
Policy Setting for personalised social supports	49
Policy Settings for income support	51
Policy Settings for habilitation.....	54
Policy Settings for resolving disputes	55
Build infrastructure for improving health & safety of communities (Year 2 – 5).....	57
Function	57
Institutional structures.....	57
Plan Transition of existing systems (Years 3 – 5)	58
Administrative model	58
Service delivery model.....	58
Transitional plan to transition current systems to future systems	58
Operationalise the future system (Years 5 – 10).....	59
CONCLUSION.....	60
POSTSCRIPT.....	61
APPENDIX 1: DISCUSSION PAPER	62
DISCUSSION PAPER	62
Expansion of ACC	62
APPENDIX 2: OVERVIEW OF RESPONSES	67
First Part of Survey.....	67
Second part of Survey.....	67
APPENDIX 3: Further details of funding options.....	70
Further discussion of Expansion principle 3: Innovation of the funding model	70
Why is innovation necessary?	70
Innovation in the ACC funding model	71
The alternative to innovation of funding.....	71
APPENDIX 4: PERFORMANCE OF ACC INVESTMENT FUND 1992 – 2021 (ACC 2021 Annual Report).....	75

BACKGROUND TO THIS REPORT

In 1967, a New Zealand Royal Commission proposed a ground-breaking new idea, a social insurance scheme to help people with impairment. No matter how someone got an impairment, how old they were, or whether they were working, they would receive ongoing care and support from a single system. To do this, we would start with people who had impairments caused by accidents and then it would expand to include all of us, regardless of how we developed our impairment.

We started this world leading work but have never taken the intended next steps, and now 50 years have passed, and the job is not finished. Our current system only helps some people to get what they need and even then, the process of determining the cause of someone's needs creates additional disabling experiences. For everyone else, the system doesn't deliver at all.

The sharp distinctions that the current system draws mean that huge amounts of public and private resources are spent arguing about the causes of impairment. People find themselves lost in a fragmented network without help, or in costly and stressful disputes with the Government, at a time when they are most in need of care and support.

Thousands of New Zealanders have told their stories over the course of this work, and they have made it clear that they want a person-directed integrated system for all people with impairments in Aotearoa. They believe that to reduce disabling experiences and live healthy and meaningful lives we need to finish the job that was started by the Royal Commission in 1967.

New Zealand has a proud history of big, bold ideas and world-leading progressive reforms. In the past, we have not shied away from significant decisions, and we should not be afraid of them now.

The transition from a fragmented system to a person-directed integrated system can be planned for, designed, and implemented over time. It will require consultation with tāngata whaikaha (disabled Māori) and disabled people and must be co-designed. It will also require capacity building and the development and implementation of a sustainable funding model. The new Ministry for Disabled People must be tasked with this work.

The legacy of our failure to implement this vision when this was raised, means our stories of discrimination and inequality have been etched in the walls of our homes, schools, workplaces, and communities for fifty years. The legacy of this failure has filled our statutes and is reflected in our judgments and countless reviews, inquiries, and royal commissions. Unless we act now, the current imperfect and unfair system will continue to be written into the stories of our

BACKGROUND TO THIS REPORT

children's children and their children. The decisions that are made in the next decade will shape the experience of generations of future New Zealanders.

Long-term projects require community support, political bravery, and vision. This means that if the change is to come, the call for change needs to come from all New Zealanders.

This report provides a road map for achieving this goal within a decade and sets out a simple choice for our future. We can become world leaders again in the field of care and support for all our people, or we can choose to perpetuate the fragmented, incomplete, and broken system that history has shown does not work.

A VISION FOR THE FUTURE

People are the heart of our communities and our society in Aotearoa New Zealand.¹ We recognise as a society that many people with impairments have disabling experiences; these can result in exclusion, and we want to change that. The vision is:

in the future we will have an integrated person-directed system for supporting people with impairments that will reduce our disabling experiences. This system will provide four enforceable rights to social support, income support, habilitation, and healthcare.²

Basis for this Vision

The foundation for this vision is that the future system:

- is not based on the cause of our impairments and does not require a diagnosis or cause before we get what we need;
- is fair and transparent so people in our society trust their interactions with Government;
- delivers four enforceable rights to social and income support, habilitation, and healthcare quickly and in a way that removes or significantly reduces disabling experiences;
- creates a society where people are healthy, safe, and have strong connections with communities and workplaces;
- and is achieved through the integration of existing systems and collaborative leadership.

Guiding Principles of Design

The guiding principles for designing the future system are that it will:

- meet the requirements of Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, and the Human Rights frameworks³ that we have committed to;

¹ Hereafter referred to as Aotearoa or New Zealand.

² The delivery mechanisms are discussed later towards the end of Chapter 3 and must be developed once key policy decisions have been made, taking into account the reforms that are currently underway and those which will occur in the coming years.

³ The human rights framework is set out below in Chapter 2.

- deliver integrated, person-directed legally enforceable rights with a person-centred dispute resolution pathway;
- innovate the funding model to ensure sustainability and equity for current and future generations;
- progressively realise the vision of the future system through a planned approach over time;⁴
- improve the health and safety of communities through creating an evidence-based system and investment in communities; and
- provide oversight and coordination between this system, the barrier identification and removal system (accessibility), the anti-discrimination system and the wider health and social systems.

Realising this Vision

This vision can be realised within a decade with the Ministry of Disabled People developing and implementing a framework to:

- Build relationships with stakeholders
- Build the economic model
- Build the data systems
- Lead the debate about, and then plan, the expansion roadmap
- Determine the policy settings of the four enforceable rights
- Build the infrastructure for improving the health and safety of communities
- Plan the transition to the future system
- Operationalise the delivery models of the four enforceable rights

⁴ The detail of this approach is in Chapter 3, which sets out one way to get from the current system through to the project phase to operationalisation of the future system.

CHAPTER 1: THE CURRENT CONTEXT

WHERE ARE WE AND HOW DID WE GET HERE?

What is the problem that needs addressing?

As has been established, the system we have now discriminates on the basis of cause of impairment. This discrimination is inequitable, unfair and illogical. The system itself causes disabling experiences⁵ for our people. This is not the vision of the original architects of the accident compensation scheme.

The current system is incomplete, and it is causing harm. It works for some people, but for many, it doesn't work at all. People receive different standards of care, and different social and income support, habilitation and healthcare based on the cause of a person's impairment. Families are expected to pick up the costs of what people in Government choose not to provide. We can change this by designing away the disabling experiences that are caused by our incomplete and fragmented support system.

Disabling experiences of everyday New Zealanders

Thousands of New Zealanders have told their stories over the course of this project and hundreds of people completed the survey.⁶ These stories were collated, analysed, and form the basis of the case studies presented in this report. The stories have been anonymised and added together as a way of representing experiences that were common to many.

Anna's story:

Anna hurt her foot and needed surgery and rehabilitation so she could stay at work. She enjoyed her job. It was great that she could get out of the house into the community, and her job meant she could maintain her relationships with colleagues and friends. ACC covered the sprain in her foot and paid her weekly compensation. ACC then obtained a medical assessment that showed Anna had a degenerative condition in her foot and ACC correctly suspended her compensation and decided not to fund her surgery.

⁵ Disabling experiences are the negative experiences of persons with impairment when impeded from full and effective participation in society on an equal basis with others.

⁶ See Appendices 1 and 2 for survey and results. A discussion paper was circulated in October 2018 with a link to a survey. This was completed by 853 people. This was not a representative sample as it was self selected, but it shows the gap that must be addressed as the themes in what people expect. Some stories are from people who have been in touch more recently with their experiences. These are included to show the ongoing issues people face.

CHAPTER 1: THE CURRENT CONTEXT

Anna's income support was transferred from ACC to WINZ and her treatment transferred from ACC to a District Health Board. She waited on the public waiting list. After 3 months off work, her employer had to give her job to someone else but kept her on unpaid leave. After 6 months, she lost her job. This meant that Anna lost her independence and hope, and she started feeling down. Anna was off work for two years in total waiting for surgery. The Ministry for Social Development (MSD) paid her more money in income support than it would have cost to have the operation when it was first recommended. The District Health Board funded the surgery and it cost a few thousand dollars less than it would have through the ACC system. Because Anna couldn't work for more than two years, even after the surgery she was not able to return to her work and she had ongoing trouble walking.

Anna believes that if she got the surgery she needed early on (as she would have through ACC), she would have been able to keep her job and her recovery would have been better. She would have lost significantly less income, remained a productive member of society, and would not have struggled with her mental health. Anna is angry that she had to go through this so that ACC could save \$8,000 in surgery costs and she thinks it cost the District Health Board \$6,000 and MSD nearly \$30,000 in benefits.

Barry's story:

Barry had a stroke. His health needed to improve, and he needed rehabilitation. He knew his social support would be on-going but he really needed to pay his mortgage while he did his rehabilitation so he could return to part-time work. Because Barry was in a relationship and his partner worked, Barry could not receive any income support from MSD. There was no agency that Barry knew about where he could get help for his rehabilitation.

Barry and his partner struggled. After eight months, they had no savings left and their relationship deteriorated. Twelve months after the stroke, they had to move out of their house because they couldn't afford it and their relationship ended. Barry had not had the rehabilitation he needed and could not return to work.

Barry is on a waitlist for an accessible house with Kāinga Ora. He's been on that waitlist for three years. Right now, he is living in a friend's garage. His health is continuing to get worse.

Barry believes that if he had the support he needed, he would be healthier and happier. His relationship may still be intact, and he would still feel like he is part of a community.

Chantelle and baby Kane's story:

Chantelle and her husband Dave were very excited to welcome their second child into the world in 2012. The birth didn't go to plan and both Chantelle and their baby Kane had serious impairments when they eventually left the hospital. Dave was heartbroken to see the people he loved struggling every day.

CHAPTER 1: THE CURRENT CONTEXT

Chantelle experienced birth injuries that required ongoing surgery and rehabilitation. Chantelle lodged a claim for treatment injury with ACC which was declined, and she was not able to access what she needed through the public health system. As a result, Chantelle felt embarrassed to go out in public and she felt unable to return to work. She also felt a sense of shame and guilt.

Kane was born with damage to his brain. The doctors involved thought that this was caused during birth and lodged an ACC claim. ACC sent the case off for an assessment and after a series of assessments they concluded, on the basis of the doctors' reports, that there was no evidence that the brain injury was not present before birth and that even if everything had been done perfectly during birth, Kane's brain may still have been injured by lack of oxygen.

Chantelle and Dave decided not to fight ACC about Chantelle's injuries, but they really needed ACC's help to take care of Kane. They spent the next 6 years fighting with ACC through the review and appeal process. After 6 years, they lost in court. Their lawyer advised them to appeal but they couldn't afford the legal fees. They now get some support from the Ministry of Social Development, but it doesn't cover any of the costs. As Chantelle couldn't return to work, the entire family is struggling on one income. Chantelle is hoping that now employers are more open to working from home, she'll be able to get some part time work, but she's been out of the workforce for nearly a decade now and she's not sure where to start trying to get a job.

Kane is now eight years old. He is struggling with his education. He struggles to get to school and struggles at school. This means he has had to move schools a lot and is now at his third school. He enjoys playing with his friends at school and is starting to read, but he finds it hard trying to make new friends every time he moves schools.

Chantelle experiences mental distress and this makes it harder for her to meet new people and to commit to things like deadlines. Fear of failure now makes it hard to try new things.

Emily's story:

Emily is now in a loving relationship and has children of her own, but she had a hard time when she was young. She witnessed and heard violence including sexual assault and the murder of a close family member. When she needed help, there was no-one there. Her family experienced shame and she was isolated from her community.

Today she continues to experience mental distress and it seems that when she needs it, there is still no-one to help until it is really bad or too late. Despite her distress, she was able to get a job and build her life up, but recently it got too much, and she found herself unable to continue working. She has had to give up her job.

Emily is not sure what the future holds. Because she can't work, it makes it very hard for her partner who now must work 7 days per week in two jobs. They

CHAPTER 1: THE CURRENT CONTEXT

have two kids aged 7 and 9 and they have used all their savings to pay their rent and now they don't know what to do.

All of this adds to Emily's distress, and it impacts on the entire family.

Fi's story:

Fi had a tough start in life. They were taken from their family and abused in care. They experience ongoing mental distress, and the impact of the abuse continues through to today. Fi was provided ACC cover but was not working at the right time so, like 99% of abuse victims with ACC cover, Fi does not receive weekly compensation. Fi receives some income support from Ministry of Social Development, but the mental health system doesn't work in a way that gives them the social support or healthcare that they need. No habilitation has ever been provided.

Two years ago, Fi developed a disease related to drug and alcohol use. Now they must try to navigate that system too.

Garry:

Garry is a 47-year-old father of two. He was diagnosed with an aggressive form of cancer that could be treated but the drugs were not funded by Pharmac. He couldn't work anymore, and finances were tight.

He had a choice between selling his house and renting to pay for healthcare or keeping the house so that his children had something after he was gone. Garry decided not to fund the treatment that would have given him the chance at life.

Because he couldn't work, he couldn't pay his mortgage. This made the last 18 months of his life very stressful for him and his children. After he passed away, the house was sold.

Harry:

Harry was born with an impairment that meant he has been a wheelchair user for much of his life. Harry experiences discrimination every day. One of Harry's friends Indie also uses a wheelchair, but they have cover from ACC because the reason they use a wheelchair was caused by an accident. Indie has a new wheelchair every few years and has more opportunities to get out into the community because ACC funds transportation. Last year, ACC brought Indie a van so they can get around more easily and because Indie gets income support from ACC, they can afford to take Harry out sometimes.

Harry and Indie have other friends who use prosthetic limbs, and they have the same experience. People who get help from ACC can have multiple limbs and more expensive prostheses with better technology. They want to do something about this so that everyone gets what they need, no matter what causes that need.

Jay:

Jay has long covid. They were working at a supermarket in Auckland as an essential worker and they were infected during the delta outbreak in August 2021. They thought that they were infected at work because the rest of the family was home in lockdown, but it could never be proven. They lodged an ACC claim, but this was declined because the contact tracing system couldn't show a contact at work.

Jay hasn't been able to work since August 2021. They need ongoing income support, but none is available. Jay's family also got covid in the two weeks after Jay tested positive. Jay's grandmother was very ill and was admitted to hospital, but the rest of the family recovered without any further problems.

These stories highlight the range of disabling experiences that people face every day. For decades, our Parliament has made laws that cause these problems for people. The reality is most of us will have disabling experiences at some point in our lives. For some of us, the lottery about which side of the boundary we fall on will determine what we experience. For others, the experiences go far beyond us and the impact on our families will be generational.

These experiences impact all of us: our families, our communities, and our leaders. These experiences cause harm to people who have already been harmed. The only reason that we perpetuate this is that the administrative systems that are meant to help don't work. This is why we must develop a new way of caring for people.

CORE CONCEPTS FOR REALISING VISION

The following section explains core concepts that must be understood for the future system. These include Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, impairment and disabling experiences. These must be consistent across all Government work, and a detailed explanation of terms has been included in related work on accessibility.⁷

The importance of Te Tiriti o Waitangi

The Treaty of Waitangi is the document that founded Aotearoa as we know it today. Te Tiriti o Waitangi is the Te Reo Māori text of the treaty. It contains a preamble and three articles but has a different meaning to the English version.

⁷ Forster, Barraclough and Barnes *Making New Zealand Accessible: a design for effective accessibility legislation* [2021] NZLFRRp 8.

This Te Reo Māori text is referred to as Te Tiriti, and it is this text and meaning that is relied upon for the development of this future system.⁸

The future system must be designed so that it gives effect to the principles of Te Tiriti. Any future system must include a governance model that delivers a contemporary understanding of what governance means. Making this system work will require innovation in governance models and will allow for the future system to be designed to realise Te Tiriti.⁹ These and other requirements of the system to give effect to Te Tiriti are addressed further in Chapter 2 (Design Principles for expansion) and Chapter 3, which sets out how to bring this vision to life, including building capacity for governance.

The Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities¹⁰ is an international human rights framework to assist in realising the existing rights for people with disabilities and this includes:

those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The purpose of the Convention is to:

promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The convention includes eight guiding principles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

⁸ He Whakaputanga me Te Tiriti (the Declaration and the Treaty) was signed by the British Crown and 543 signatories by rangatira (compared to 39 signatures on the English version).

⁹ Report of the Working Group on a Plan to realise the United Nations Declaration on the Rights of Indigenous Peoples: He Puapua, October 2019, see generally co-governance models being developed by Māori and the Crown.

¹⁰ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

New Zealand ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008¹¹ but the rights have still not been realised. The principles are routinely ignored. Disabled people face discrimination, exclusion, inequality, and inaccessible environments. Until now, little progress has been made to develop legislative systems to give effect to the Convention (and other relevant conventions). This is addressed further in Chapter 2 (and included in the first principle for expansion). Chapter 3 sets out how these can be realised.

Impairment must be inclusive of all impairment

The report includes a concept of **impairment**. This must be widely defined in an expanding definition so that it includes physical, sensory, psychosocial, learning, neurodevelopmental, communication, energy, and age-related impairments.¹² Much of the fragmentation is caused by the requirement for disabled people to select a “box” for their impairment before they can access systems for support, habilitation, and healthcare.

This is often done by governments to ration the provision of supports. The boundaries of these systems create disabling experiences. For this reason, it is recommended that the future system includes a wide and inclusive definition of impairment and removes boundaries between systems.¹³

At times this report refers to “people with impairments”. This is an expression used to refer to those of us who live every day with impairments and the disabling experiences that are present in so many aspects of our lives. This expression does not condone a medical model or suggest that people are impaired. It is recognised that the term “disabled people” is favoured by many people in the disability community in Aotearoa and internationally as it highlights that people are disabled by society. This report reflects this aspect of the social model by using the term “disabling experiences”.

¹¹ Disability (United Nations Convention on the Rights of Persons with Disabilities) Act 2008 Act.

¹² It is noted that there are different terms used by the United Nations Committee on the Rights of Persons with Disabilities and the New Zealand legal system. Other possible descriptive terms include “mental”, “intellectual”, “neurodiverse” and others.

¹³ These boundaries are currently being strengthened, not removed. For example, through the exclusion of mental ill-health from the Ministry for Disabled People, and the creation of the new “income insurance scheme”.

A COORDINATED SYSTEM FOR REMOVING DISABLING EXPERIENCES

Disabling experiences

For the purposes of this work, disabling experiences have been identified as:

the negative experiences of persons with impairment when impeded from full and effective participation in society on an equal basis with others.¹⁴

This can be contrasted to the wider idea of disability that includes identity and belonging to a community. This report does not define disability, as this is the role of disabled people and their organisations. Any statutory system must take a similar approach.

Any definition must be something that disabled people are free to design themselves, and any definition of “disability” must be allowed to continue to evolve. Any legislative models that are developed and implemented to reduce disabling experiences must allow for this evolution to occur in the decades to come.

The key policy goal for the future system described in this report, and in parallel work on accessibility,¹⁵ is to minimise disabling experiences. It must be recognised that a system that provides a new model of enforceable rights cannot do this work alone. That is because even with the creation of enforceable rights, systemic barriers and discrimination will continue to create disabling experiences. To be successful in minimising these negative disabling experiences, we must have three effective complementary legislative systems that are coordinated across our society.

This report, and other related work, sets out these complementary systems and explain how they will operate so that disabled people can identify and remove these disabling experiences. This is reflected in “coordination” being the sixth guiding principle of expansion.¹⁶ This coordination to systematically remove disabling experiences must cover the three inter-related legislative systems for:

- enforceable rights
- accessibility
- preventing discrimination

¹⁴ Taken from preamble to Convention at (e) and modified beyond “disability”.

¹⁵ Forster, Barraclough and Barnes *Making New Zealand Accessible: a design for effective accessibility legislation* [2021] NZLFRRp 8.

¹⁶ See below at Chapter 2, Guiding Principles for Expansion.

System of enforceable rights

This is a new system proposed in this report to create enforceable rights¹⁷ for persons with impairments to personalised social support, income support, habilitation, and healthcare. Creating this new system will meet the principles of the Convention on the Rights of Persons with Disabilities, empower people to live their best life, and increase choice and control. These would be provided by the state through a centralised administrative system for people with impairment similar to the way entitlements are currently available under the ACC system. This includes modifications, adjustments and supports for a person with impairment, to ensure their enjoyment or exercise of all human rights and fundamental freedoms on an equal basis with others.

These are all, in theory, existing rights that should already be provided through a “rights-based” framework. Disabled people know that these are not enforceable, not effective and are not provided in a person-centric manner, let alone person-directed. This report focuses primarily on developing a system to create enforceable rights, and then to implement this system over the next decade. Whilst the system of enforceable rights has an important role to play in removing disabling experiences, the future system will not be able to remove many of the wider systemic barriers.

System for Accessibility

Barriers are negative features of an environment that typically cause disabling experiences for many people with impairments. In this context, the reason that the feature is negative, is because it interacts with people’s impairments to prevent them from full and effective participation in society.¹⁸

The system for identifying and removing barriers has been designed in another research project which complements the proposals in this report.¹⁹ This system is also designed to include principles of progressive realisation, meaning it will be developed and implemented over time to remove barriers.

The Government is currently progressing the Accessibility Legislation, and this was introduced into Parliament on 2 August 2022.

¹⁷ Rights can be read down or balanced against other things, for example in the New Zealand Bill of Right Act. The phrase “enforceable rights” is used to reflect the fact that these rights are positive rights for disabled people to enforce against the state in the same way that entitlements can be enforced through the ACC system. It is recommended that the future system moves away from using the word “entitlement”.

¹⁸ This is based upon the UNCRPD definition, and the definitions set out in the Canadian Federal legislation and others without the specific domains being mentioned. See *Making New Zealand Accessible* for further discussion.

¹⁹ Forster, Barraclough and Barnes *Making New Zealand Accessible: a design for effective accessibility legislation* [2021] NZLFRRp 8.

System for Non-Discrimination

Non-discrimination and reasonable accommodations are obligations upon all people and organisations in Aotearoa. The existing system for this is currently described as the Human Rights system.²⁰ It is created through the Human Rights Act 1993 and operationalised through the Human Rights Commission and the Human Rights Review Tribunal.

This existing system requires that reasonable accommodations be provided in specified circumstances to disabled people and prohibits discrimination. There are numerous issues with the existing system, and it is viewed by many disabled people (and others) as ineffective at removing disabling experiences.

There are numerous exceptions and many other issues with the existing anti-discrimination system. It is widely viewed as ineffective despite the hard work and dedication of those who work in the system. Having acknowledged this, any review of the system preventing discrimination is beyond the scope of this research project but having an effective, functioning non-discrimination system is required if progress is to be made in removing disabling experiences.

PEOPLE WANT THE GOVERNMENT TO CREATE A SINGLE SYSTEM

In the first year of this project, New Zealanders were invited to read a discussion paper and complete a survey²¹ to understand views on what people wanted the Government to do and why. Hundreds of people took this opportunity. A thematic analysis was undertaken. Respondents overwhelmingly said that they want an integrated system for all of us living with impairments to reduce disabling experiences so we can live the best lives we can.

The transition from a fragmented system to an integrated system can be planned for, designed, and implemented over time. It will require consultation with disabled people, including disabled Māori, and must be co-designed, it will require capacity building and the development and implementation of a sustainable funding model. Chapter 3 of this report sets out one approach to do this.

²⁰ It must also be noted that in New Zealand, the Human Rights system is not “absolute”. Because of our current constitutional system, we cannot go to Court and enforce our human rights in the same way people in some other countries can. We can go to the Human Rights Commission and Human Rights Review Tribunal and enforce anti-discrimination provisions and make demands for reasonable accommodations, but that is it.

²¹ See Appendix 1 for discussion paper and Appendix 2 for summary an overview of responses.

People agree with the vision

New Zealanders agree with the vision, and they want a system that works for them. They want healthier and safer communities, and they want persons with disabilities to have improved social and financial capital. They want an integrated person-directed system for all of us. People are not satisfied with the fragmented system, and they want the Government to fix this.

A single integrated system will bring benefits for our people with impairments

The people who completed the survey said that having a single system for all people with impairments would:

- improve peoples' experience with the Government systems
- improve access so that disabled people can get the help they need when they need it
- reduce peoples' disabling experiences
- increase fairness
- reduce inequality
- improve dignity and respect.

A single integrated system will bring benefits to us all

People said that having a single system would also bring systemic improvements because it will:

- reduce the negative disabling experiences
- provide better information
- create healthier and safer communities
- create a more effective system (it works better)
- create a more efficient system (the cost of running the system is less).

People want the Government to act

New Zealanders want the Government to act. People think that our leaders are aware of the problems and some of the solutions but will only act if there is a plan on how this can be done and we demand action.

People want our leaders to recognise:

- that this is more than an inconsistency – it creates an injustice that drives inequality in our society
- that this is a legitimate issue that must be addressed
- there is a way to address these issues

- people want these to be addressed
- if these decisions are not made now, they will become harder to make in the future.

WHAT NEEDS TO BE DONE SO WE CAN MOVE FORWARD?

Five questions must now be answered so that we can move forward:

- Do we agree on the vision?
- Do we agree on the four enforceable rights?
- Do we agree on the six guiding principles for expansion?
- Do we agree on implementing the 14 recommendations?
- Do we agree to work together to develop a roadmap?

The proposed vision for the future system is:

in the future, we will have an integrated person-directed system for supporting people with impairments that will reduce our disabling experiences. This system will provide four enforceable rights to social support, income support, habilitation, and healthcare.

This vision is one that all our people can agree to. It is inclusive. It is fair. It will increase equity and it can be achieved in a decade. The ideas of Sir Owen Woodhouse set out at the beginning of this report are not new ideas. They have been repeatedly raised through the decades but have never been fully realised.

These can be realised by the creation of four enforceable rights and using a principled based expansion towards that future system.

The risk of agreement not being reached is that another generation of our people will pass without these issues being addressed. This means another generation of hardship and lives not lived to their full potential. It means increasing inequality and it means further intergenerational inequity.

CHAPTER 2: THE FUTURE SYSTEM

THE FOUR ENFORCEABLE RIGHTS OF THE FUTURE SYSTEM

The four enforceable rights²² of the future system for persons with impairment are (1) personalised supports, (2) income support, (3) habilitation, and (4) healthcare.²³

The enforceable right to personalised social supports

Social supports enable us to live the best lives we can and allow us to be connected to a community. The enforceable right to personalised supports reflects that this right is held by the person, and it is enforceable. This must be person-directed.²⁴

There are a number of processes for providing social supports using a social model of disability without the need for the person's impairment to be "assessed" or support to be controlled through a medical model. Central to any model will be providing the person with choice and control to give effect to the person-directed approach. The enforceable rights to social supports must be available throughout a person's life.

This type of support is provided for some people through the existing Enabling Good Lives model, and for others through social rehabilitation entitlement in the ACC system. It is one of the focuses of the new Ministry for Disabled People. It is important because it helps our people live independent fulfilling lives by providing what they need to live independently, connecting people to communities and helping to build social capital. To be effective, it must be available as soon as it is needed. This can be provided through a social model of disability. By creating a future system that includes personalised supports we can design away the requirement to determine cause (or who should fund it) before support can begin.

²² These enforceable rights could also be described as "entitlements", which has negative connotations, and should be distinguished from a view of rights as something to be balanced against "obligations or responsibilities".

²³ There must be administrative systems for the delivery of these enforceable rights so that these are realised, and the disabling experiences are reduced. The system for doing so must be carefully designed in accordance with the principles for expansion and following a clear design process. An example of this is set out in Chapter 3. It is noted here to emphasise the importance of this function.

²⁴ The term "person" rather than "individual" should be preferred as it allows a person to be considered in their context, for example within their whānau rather than simply as an individual devoid of family or community.

Enabling Good Lives provides a principle-based approach.²⁵ It is useful to consider these principles and how they can be improved. In particular, “person-centred” could be updated to “person-directed” to reflect true choice and control, and it could be recognised that the current “mainstream first” approach does not overcome the systemic barriers. Either we change the mainstream or create a system of enforceable rights for people with impairments. These can be delivered within a mainstream system (see Chapter 3 discussion on service delivery), but they must be enforceable to be effective.

As the system is expanded, social supports must not be removed just because a person’s earning potential increases and their need for income support diminishes. This is because the need for social support often remains even after a person’s need for income support reduces. Given the cultural context in Aotearoa, this should be framed as personalised rather than individualised, as this better reflects how personhood is considered in te ao Māori.

The enforceable right to income support

Income support is to replace income from work for people of working age who cannot work. This would start at working age and end at superannuation age.

This would replace weekly compensation that is currently provided through the ACC system, and income support payments provided through the Ministry of Social Development. It must be implemented using a person-directed model and must not discriminate based on relationship status.

The link between participation in paid and unpaid “work” and health and social outcomes is well established.²⁶ It is also clear that people want to work, but the systems we have created exclude many people from participating in the labour market and significantly limit the effective participation of many others. By creating an enforceable right to income support *and* effective habilitation to complement the accessibility system and strengthening the system for preventing discrimination, our society will start to see the benefits of paid and non-paid work.

As employment outcomes are created through habilitation, the need for income support will reduce for some people, but for others, it will take significant time, and for others it may not be possible at all. Importantly, if a systemic approach is taken to improving employment outcomes, then productivity will also increase as habilitation is likely to assist tens of thousands of disabled people into meaningful employment.

²⁵ <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/>

²⁶ See for example OECD (2018), *Mental Health and Work: New Zealand*, Mental Health and Work, OECD Publishing, Paris. <https://doi.org/10.1787/9789264307315-en> ISBN 978-92-64-30731-5.

It is recognised that there is currently a proposal to provide an income insurance system.²⁷ How this potential system interacts with the future income support system will need to be carefully managed. It is worth noting that the current proposal for income insurance states that it will help address inequity where a person who experiences an accident can receive more support than a person with non-accident-related health conditions.²⁸

The proposed income insurance system may assist people with short-term conditions (12 months or less) who are established in the workforce when their need for income support first arises. The income insurance system, as proposed, will do little to remove the disabling experiences faced by most people with impairments as many are excluded from employment to begin with,²⁹ and when the need for income support for disabled people arises, about half the people are still receiving this after two years.³⁰ The policy setting required for this must be carefully considered and the new Ministry for Disabled People will need to take an active role in determining these to avoid replicating the discrimination created by the ACC legislation in the proposed income insurance system.³¹

The enforceable right to healthcare

The future system must provide for a person's health in a holistic sense. This includes physical and mental health for the duration of a person's life. Decisions related to health must be made by the person exercising informed consent with choice and control following interactions with and advice from professionals in a treating relationship. The current system discriminates based on the type of treatment and why a person needs treatment.³² This means that before treatment can begin, administrative systems often require a "diagnosis" and a "cause" even when the treatment required is clear. In other cases, limited treatment can begin with a provisional (or interim) diagnosis. By removing the need to confirm *why* a person needs healthcare before they can access that healthcare, we remove the administrative requirement, and people will be able to access the health services earlier.

There are numerous policy decisions that must be made about this enforceable right to healthcare. Some of these are mentioned below in Chapter 3. It is intended that in the first instance this right relates to healthcare for people with impairments. Ultimately, the relationship between this right and the wider health system will need to be developed further. Nonetheless, one significant barrier

²⁷ A New Zealand Income Insurance Scheme: A discussion document, 2 Feb 2022 ISBN 978-1-99-102237-0,

²⁸ Ibid at p 98.

²⁹ In three month to end of June 2021, 42% of disabled people of working age (15-65years old) are in work (Stats NZ, 17 Aug 2021).

³⁰ Ibid. Annex 3, page 160-162.

³¹ It is noted that the proposed income insurance system will not be integrated with treatment.

³² The ACC system funds some treatment each year for around 40% of the population. ACC Annual report, 2021.

needs special consideration. Primary healthcare in Aotearoa acts as a gatekeeper for accessing secondary and tertiary treatment, and acts as a barrier for people with impairments. As a result of this and other barriers, many disabled people have a life expectancy that is decades shorter than others.

For the enforceable right to healthcare to be realised, primary healthcare must become accessible for *all* people and the barriers between physical and mental health must be removed. If this is not done, we are not going to make significant progress on health and wellbeing for people with impairments. To remove this barrier, we must innovate the way we fund our health system and deliver services to people. This report proposes a way to do this.

The enforceable right to habilitation

Habilitation is a process of active change aimed at helping people gain, regain, or retain the skills, abilities, and knowledge they need to achieve their goals and remove disabling experiences. It involves things that help people to create change in their lives. It is person-directed and planned. It can stop, start, and change as required. It includes:

- processes aimed at increasing independence
- specific tools that help people for example assistive technology, aids and appliances that increase independence and inclusion
- the discovery process and customised employment in relation to paid and unpaid work.

Habilitation is different from social support (that continues throughout a person's life) because habilitation starts and stops as required. It is different to healthcare which is focused on treatment. In the future system, the enforceable right to habilitation will begin at a specified point in a person's life³³ and continue alongside that person as they transition from the education system and continues for life.

Adding additional enforceable rights

It must be acknowledged that there are numerous "rights" contained in human rights frameworks, disability strategies, the New Zealand Bill of Rights Act, international human rights instruments, and other legal instruments that have not been included in this list of four enforceable rights.

Many disabled people consider that other rights should be included in the future system, particularly the right to housing and the right to education. It is currently not proposed to extend a positive enforceable right to either housing, education, or employment in the proposed system of enforceable rights.

³³ This point must be before the minimum school leaving age, currently 16 years old, and in some circumstances, 15 years old.

It is possible that the four positive enforceable rights set out above could be expanded over time. It is also possible that by creating these four enforceable rights, and coordinating between this system, the accessibility system, and the discrimination prevention system, many of the other rights will begin to be realised.

GUIDING PRINCIPLES FOR EXPANSION

The guiding principles for designing the future system are that it will:

- meet the requirements of Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, and the other Human Rights frameworks that we have committed to
- deliver integrated, person-directed legally enforceable rights with a person-centred dispute resolution pathway
- innovate the funding model to ensure sustainability and equity for current and future generations
- progressively realise the vision of the future system through a planned approach over time
- improve the health and safety of communities through creating an evidence-based system and investment in communities
- provide oversight and coordination between this system, the barrier identification and removal system (accessibility), the anti-discrimination system, and the wider health and social systems.

The next pages summarise these principles. Further detail for some is included at Appendix 3.

Expansion Principle 1: Te Tiriti and Human Rights compliant by design

We must meet the requirements of Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, and the Human Rights frameworks that we have committed to; including the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the Declaration on the Rights of Indigenous Persons, and the Sustainable Development Goals.

What obligations exist on the Government?

The New Zealand Government has long-standing obligations based on the Te Tiriti, and over recent decades it has committed to the United Nations Conventions and Declarations, including on the Rights of Persons with Disabilities, the Rights of Women, the Rights of Children, the Rights of Indigenous Persons, and the United Nations Sustainable Development Goals.

Whilst the New Zealand Government has committed to providing the rights and protections under the Conventions, to give effect to them in law, they need to be incorporated into our national laws and policies. If the legal and policy instruments cannot reasonably be interpreted in a way that meets the conventions, then our courts have no choice but to enforce the existing laws. This often means that people have no way to enforce their rights and the obligations under the conventions if these are not met.

The New Zealand Government has created a series of law and policy instruments dating back two decades³⁴, but these are ineffective. Disabled people know that these don't work to remove disabling experiences. The United Nations Committee on the Rights of Persons with Disabilities has made it clear that the New Zealand Government is not meeting its obligations.³⁵

This means that change is required. Parliament must make laws that give effect to these obligations. This report does not propose that New Zealand should take on new obligations. Instead, it explains that to meet our commitments, the Government must incorporate the principles of Te Tiriti o Waitangi, and its commitments under the United Nations Conventions and Declarations into the design and expansion towards the future system. The priorities and the roadmap should be developed in close consultation and partnership with disabled people, women, Māori, children, and organisations that support these groups.³⁶

No country has yet enacted effective laws to bring themselves fully into line with the Convention on the Rights of Persons with Disabilities, but we can start the process now to do this. If we can have an agreement on a vision and a plan for working towards this vision that will progressively realise our obligations, then we can achieve this.

³⁴ See Forster, Warren; Barraclough, Tom; Barnes, Curtis "Making New Zealand accessible: a design for effective accessibility legislation" [2021] NZLFRRp 8 at 22-23 for a summary and discussion of these.

³⁵ Concluding observations on the initial report of New Zealand: Committee on the Rights of Persons with Disabilities CRPD/C/NZL/CO/1 and United Nation's List of 100 Issues, 2018.

³⁶ See Chapter 3.

Recommendation for Principle 1: Te Tiriti and Human Rights Compliant

Recommendation 1.1:

It is recommended that the first principle of expansion is that the future system is designed to meet obligations under Te Tiriti and to provide the rights set out in international conventions, focusing on the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the Declaration on the Rights of Indigenous Persons, and the Sustainable Development Goals.

Recommendation 1.2

It is recommended that the Government require the Ministry for Disabled People to comply with Recommendation 1.1 in all policy development.

Expansion Principle 2: Create integrated person directed service and person-centred dispute resolution services

We must deliver integrated, person-directed legally enforceable rights with a person-centred dispute resolution pathway for all people with impairments.

What is meant by Integration?

The systems we currently have for helping people are fragmented and they can be very difficult to use. There is fragmentation within each system, for example, when someone needs surgery, should this be funded by ACC or the public health system? When someone needs social services, they interact with a social system that has already faced a century of fragmentation.³⁷ This fragmentation also occurs between the current systems for social and income support, healthcare, and habilitation, for example whether what someone needs should be provided by the health system or the social system. In the same way, when people talk about integration, they can mean different things.

Integration within the system for providing a single enforceable right

People can mean integration between different ways of funding health or social support. For example, there could be integration in the health system so that people only need to go to one organisation to obtain each of their enforceable rights. For treatment, people would go to either the public health system or the ACC system to get the treatment they need, but they don't need to go to both. This type of integration could be achieved now by the new health system being

³⁷ Productivity Commission More Effective Social Services ISBN: 978-0-478-44021-8 (print), at page 251.

directly funded by ACC to deliver services so there is functional integration at the point of service delivery for that one service. Similar approaches could be taken to income support, for example between ACC, the Ministry of Social Development (MSD), and the proposed income insurance system.

The problem with this approach is that people would have to go to one organisation to get social support, and a different one to get income support, a third to get habilitation and a fourth for healthcare. Boundary disputes will be reinforced between the health system, the social system and the income support system, and there will be no effective system for habilitation. These boundaries will become difficult to administer and are unlikely to be overcome through new ways of thinking about the public service.

Integration between systems for providing four enforceable rights to provide a single system for helping people

Integration could also mean a person with impairments going to one organisation to get all their enforceable rights. For example, a person with cover from ACC who was working at the time and has an “injury” which means they’re off work for 6 months can often go to ACC to get the social and income support, healthcare, and habilitation they need. It is this type of integration that is proposed as the principle of the future system. It is about integrating the four enforceable rights so that they can be person-directed.

This integration will design away the need for a specific diagnosis and to determine the cause of a person’s impairments before they can get what they need. It will also design away the need to go to a different place to get healthcare, social support, income support and habilitation. It will reduce the need for assessments and will be fair and transparent so people in our society trust their interactions with our Government. It will deliver healthcare, social support, income support and habilitation quickly and in a way that removes or reduces disabling experiences. It will allow the vision for our future system to be achieved.

Person directed service

A person-centred service is where the services are there for the person within their family/whānau and community. If a service is created that is person centric, when a person needs help, they do not have to try and navigate the system themselves and they don’t need to do it with the help of a navigator. All parts of the system that they need come to them.

A person-directed service takes this approach one step further, and incorporates the person’s right to choice and control. In this way, not only are

the services there for the person, but the person is supported in their decision-making.

To have a single person-directed system, we must have functional integration at the point of service delivery, and integration between the four enforceable rights. This means that it makes no difference to the person which agency funds the service they need, and whether that need is characterised as a health need, a social need, or a habilitation need.

New Zealanders' have said they want a single system.³⁸ There are several ways to deliver this integration, but the key is that when the service is delivered, it is person-directed.

The recommended approach is total integration at a system level for each of the four enforceable rights to remove the incentives for cost shifting, and to deliver saving by removing the duplicated administration and assessment costs. If this does not occur, then functional integration at the point of service delivery is the minimum possible level of integration.

Person-centric dispute resolution system (non-adversarial first steps)

Access to justice is central to the development of the future system. As the system expands, many of the disputes about what causes the need will be removed, but there will still be disputes and a system for people to enforce their rights. When disputes arise, the primary focus must be on resolving them in a timely manner in a way that removes barriers to access to justice. The formal justice system cannot continue to be used as a mechanism to constrain resources.

There have been well known problems with access to justice within the accident compensation system. Significant work is underway to transform the way people experience disputes with ACC. The changes are being implemented and these have shown promise in effectiveness, efficiency, and experience.

Any system will generate legal disputes and this needs to be recognised, but the current models for resolving disputes need to be reformed to implement a person-centred first step. The newly developed ACC navigation service and early dispute resolution conciliation service provide a starting point for this.

There is an emerging approach to dispute resolution, which is that accountability and system learning, and improvement are incorporated into the dispute resolution system.³⁹ This must be embedded into the future system.

³⁸ See Appendix 2.

³⁹ See for example the Government Centre for Dispute Resolution principles and maturity improvement framework and the Education (Domestic Tertiary Student Contract Dispute Resolution Scheme) Rules 2021.

Integration of health, social, financial & habilitation outcomes

Any future system must integrate health, social, financial and rehabilitation outcomes under a single model. This is the most effective way to remove cost shifting over arbitrary boundaries, and to remove the costs of enforcing and defining the boundaries. We have no direct evidence of the cost of administering boundaries within the various fragmented systems as the agencies do not collect this information. Based on what is known about the administrative costs of ACC, the health system and the welfare system, there will be significant cost savings (likely in the billions of dollars annually) by removing the requirements for administering the boundaries within and between these systems.

Failure to integrate services will see continued fragmentation of services. If one department or agency provides healthcare, and a different one provides social support, and another one provides income support, and no-one provides habilitation, then the opportunity to provide integrated services and outcomes will be lost. The proposed income insurance system fails to provide integration and the issues caused by this will be seen as it is developed.

Recommendation for Principle 2: Person-directed integrated system with person-centred dispute resolution

Recommendation 2.1

It is recommended that the Government commit to developing a person-directed system for people with impairments that is delivered through an integrated system of enforceable rights to social and income support, habilitation and healthcare, with monitoring to ensure choice and control along with measurable outcomes for people.⁴⁰

Recommendation 2.2

It is recommended that the Government commit to implementing a person-centric dispute resolution model to allow people to enforce their rights under the future system.

Recommendation 2.3

It is recommended that the Government task the Ministry for Disabled People with the policy development to implement recommendations 2.1 and 2.2.

⁴⁰ Care must be taken to avoid the approach of blaming a person if the outcomes are not achieved in their individual case or removing choice and control, and access to justice from this process.

Expansion Principle 3: Innovate the funding model

We must innovate the funding model to ensure sustainability and equity for current and future generations.

What is meant by funding model?

When people talk about “funding”, they sometimes mean two different things. Funding can be used to describe how money is collected and organised to fund systems, for example through taxes or levies or use of a sovereign wealth fund. Or it can be used to describe how this money is distributed to people or service providers to pay for things. Both are important to think about, but the focus on this guiding principle for expansion is on organising and collecting funding for the future system, rather than on distributing it.⁴¹

Why is innovation in funding necessary?

There are a limited number of different ways to fund health and social services. Historically, these have been mainly based on revenue from taxation in New Zealand. This thinking is best demonstrated by the recent Health and Disability System Review. Its focus was on efficiency and effectiveness⁴² rather than innovation of the funding model. The same process has been followed in the proposed income insurance scheme which will set a new levy to fund the annual costs of that scheme.

Nearly all reviews that are undertaken in relation to health and social services in Aotearoa focus on how money is spent and setting ways to collect money that year to pay for the costs of that system. We must change this and think about how we can use different funding models.

We cannot continue to rely on taxation (or levies) to fund the future system. This is the approach that has been taken for decades. There is widespread agreement that it is not possible to fund the growing costs of health and social services from taxation without increasing taxes. The result has seen the development of more complex rationing tools that shift the cost from one organisation to another organisation to individuals and families. Importantly, this cost doesn't go away. Our Government has developed initiatives aimed at

⁴¹ Questions around how the money is distributed will need to be determined as the policy settings are developed. These are outlined towards the end of the next chapter as part of the development of the policy settings. This is also discussed as part of the service delivery. Once decisions are made on how services are to be delivered, then decisions will need to be made on how those services will be funded.

⁴² Health and Disability System Review. 2020 *Health and Disability System Review – Final Report – Pūrongo Whakamutunga*.at page 57.

constraining health inflation, for example, Pharmac purchasing models and public/private cost splitting. Nevertheless, this focus on rationing tools and constraining costs has taken focus away from innovating the funding model.

We need to innovate how we fund the future system.

Recommended innovation is to develop a perpetual sovereign wealth fund

It is proposed that the innovation takes the form of a sovereign wealth fund.

There are limited international examples of using sovereign wealth funds to fund health and social services in the way proposed in this report. The closest example, which is still significantly different, is the Singapore health system. This uses several large sovereign wealth funds to fund individualised healthcare. This means in Singapore, a person contributes to the fund and gets returns which they can spend on themselves or their family. The significant difference between the Singapore model and the proposed future system set out in this report, is that the return on investment is spread across the system and used to fund the gap between taxation or levy collection and health and social inflation at a system, rather than individual, level.

The ACC fund is now over \$50 billion. The estimated return on investment for this fund in the last nine years is \$29.7 billion. The estimated cost of providing the four enforceable rights of the future system (social and income support, healthcare and habilitation) to those currently covered by ACC was \$34 billion.⁴³ If the cost of administration over this period (estimated to be \$6 billion) could have been halved by reducing the boundary assessments and administration, then a sovereign wealth fund model could have been largely self-sufficient without the need to collect levies. This is remarkable, and as the fund grows the likelihood increases that over a decade the return on investment is higher than the costs of providing the enforceable rights.

If 80 to 90% of the \$50 billion from ACC was removed from the day-to-day control of ACC and put into a sovereign wealth fund for the future system, it could then grow for the next five to eight years as the future system is developed. Some of the fund should remain within ACC's direct control to allow for any financial shocks.

Once the fund reaches its designated levels (for example \$100 billion, which is likely to take less than a decade), then some of the return on investment could be returned to the fund each year to cover inflation and provide a contingency for any financial shocks, with the remainder of the return on investment being used to cover the progressive realisation of the future system. To be

⁴³ Analysis has been provided for the past nine years (2012-2021), see Appendix 3 for tables and calculations.

sustainable, the fund does not need to cover the entire cost of the future system, instead it needs to provide a buffer between income from taxation and levies on one hand, and inflation in the costs of the four enforceable rights on the other.

Using a model like this allows for the future system to be developed in a financially sustainable way. It also increases intergenerational equity.

The idea of sovereign wealth funds is now well established. There is an international association of sovereign wealth funds,⁴⁴ and an agreed set of governing principles on investments known as the Santiago principles.⁴⁵ It must be acknowledged that at times, the use of sovereign wealth funds has been controversial, often due to tinkering and political interference about important questions like how capital is put into the fund, how it is invested, and when and how the capital will be removed from the fund and spent. The solution to this is to develop multi-party political consensus on the structures, funding into, and use of the sovereign wealth fund.

Removing the outstanding claims liability from the ACC system

The ACC fund is now approaching the level where the return on investment is similar to the annual expenditure on the four enforceable rights.⁴⁶ Interest rates are rising and the outstanding claims liability is dropping, so sometime in the next few years, the outstanding claims liability is likely to be below ACC’s financial reserves for the first time in its history.

Table 1: ACC Reserves and Outstanding Claims Liability 2015-2021.

Year (1 July – 30 June)	Reserves	Outstanding Claims Liability
2015/2016	34.8	36.7
2016/2017	36.6	37.7
2017/2018	39.6	40.6
2018/2019	43.8	53.3
2019/2020	47	61.5
2020/2021	50.3	55.4

This proposed innovation will have a further benefit in that it removes the requirement for ACC to “fully fund” its “outstanding claims liability”, which is the cause of significant problems within the scheme. The ACC system could operate on a pay as you go model as the future system is developed, and if the income insurance system is progressed, it could operate on the same basis.

⁴⁴ International Association of Sovereign Wealth Funds (<https://www.ifswf.org/>).

⁴⁵ <https://www.ifswf.org/santiago-principles>

⁴⁶ Returns from 1 July 2017 to 30 June 2021 are estimated at \$16.7 billion and costs for four entitlements are estimated at \$18.1 billion.

This is a unique time in the history of the ACC scheme. A decision could simply be made for ACC to be expanded, using the surplus to pay the costs of expanding the scheme to non-accident related disabilities. However, this approach will be undermined when interest rates drop again, and the outstanding claims liability increases. For this reason, a long-term sustainable funding model must be developed and implemented.

Introduce a levy to increase the size of the wealth fund

If there is consensus to introduce this scheme more quickly, for example in two to four years, then consideration must be given to introduce a levy system to increase the level of the sovereign wealth fund. This could be introduced in the short-term to grow the fund, or the mid-term to maintain the level of the funds. There are numerous options for a levy system. Significant policy work must be undertaken before going down this path.

In its simplest form, the future system could begin sooner if a levy was imposed to help build the fund, or later if the condition upon which expansion begins at the point in time when the fund reaches the set figure through growth alone (ie. without adding additional capital). Examples of these approaches are set out in Chapter 3 as part of the roadmap for expansion.

Other funding options

If the sovereign wealth fund model is not considered appropriate, then other funding models could be considered. These are explained further in Appendix 3 and include:

- Implement legislative requirements to increase funding
- Relying on political consensus to prioritise disability, health and social services
- Borrowing money each year to fund the provision of health and social services
- Increase taxes each year as required to fund the additional costs
- Develop more and more complex rationing tools to control resource allocation
- Develop a private insurance model.

None of these options has the same potential to improve equity, provide sustainability, and ensure that increasing health and social inflation don't result in rationing of services, and therefore these are not recommended for the future system.

Recommendations for Principle 3: innovate the funding model

Recommendation 3.1

It is recommended that the Government commit to innovating the funding model to fund the provision of enforceable rights for people with impairments to provide long-term sustainability and equity for current and future generations through the future system.

Recommendation 3.2

It is recommended that the Government removes the outstanding claims liability from the ACC system, and transfers 80% to 90% of the ACC investment fund into an independent sovereign wealth fund planned for growth until the operationalisation of future system.

Recommendation 3.3

It is recommended that the Government tasks the Ministry for Disabled People, in partnership with ACC and Treasury, to undertake the policy work in relation to the economic modelling for the future system, including the timeframes for expansion.

Expansion Principle 4: Progressive Realisation

We must progressively realise the vision of the future system through a planned approach over time.

No-one imagines that the future system can be delivered overnight. At the same time, no-one wants to wait another 50 years before the vision is realised.

The suggested approach would be to plan the expansion and then progressively bring this to life over the next decade. This doctrine of progressive realisation is not new. It is reflected in the Convention on the Rights of Persons with Disabilities at article 4(2). There is much debate to be had regarding how long this will take and how it will be funded. These are questions that must be answered but detailed data on cost, and the timetable for expansion, sit alongside numerous policy decisions that must be made about the expansion. These will be determined by New Zealanders and our political leaders as they engage in the debate.

The policy choices on expansion of the system including expansion by:

- Impairment or age (level of impairment, cause of impairment, type of impairment or age at diagnosis or assessment, or geographic location),
- type of support (social and income support, habilitation and healthcare),
- individual or employer choice,

- a rights-based social investment approach, or
- when the economic conditions meet certain criteria (for example the sovereign wealth fund meets a certain level).

Which approach to follow will ultimately become a political decision and debate on the approach to expansion must be encouraged. Nonetheless, this debate must be informed. Before these policy choices are debated, there is a need for important policy development work to be undertaken, costings prepared, and the political, legislative, and institutional frameworks developed.

By impairment or person specific characteristics

The first option is to expand based on characteristics of the impairment or the person. This includes assessing how impaired a person is against a medical or functional model, or assessing the cause of this impairment. The next is by type of impairment, which might see impairments people are born with included first, then mental health, then cancer and then diabetes. These options recreate the assessment problems and the causation problems seen in the ACC system. There is also the issue where a person has more than one type of impairment.

Another option is person-specific, for example the person's age or geographic location. Income support might start for those aged 18-25 years old, or social support might start from those born in 2023 onwards. Geographic locations could follow a similar approach to Enabling Good Lives where it is piloted in a particular region.

One enforceable right at a time

This approach to expansion might see the future system start with social support, followed by income support, then habilitation and healthcare. This would improve equity across impairment types, ages, and geographic locations. The benefits of integration would not be seen until the expansion to all enforceable rights is completed.

Individual choice or employer choice

This could be based on whether someone is working (for example the proposed income insurance scheme) or whether they chose to be part of it (for example a voluntary approach like the KiwiSaver scheme). The disadvantage of this is that it exacerbates the existing discrimination as many people living with impairments have lower participation in the labour market or are underemployed.

A rights-based social investment approach

The future system could be progressively realised using a social investment modelling approach. This would provide a series of decisions to be made over time based upon robust modelling and cabinet level decisions. To do this, the social investment model must include wider benefits to individuals and communities, not just cost to the taxpayer.

When the economic conditions meet certain criteria

The economic conditions could be set so expansion commences when the sovereign wealth fund meets certain criteria (for example \$100 billion) or when the projected sustainable return on investment is a set amount (for example \$5 billion) per year higher than inflation. Another option, if the recommended sovereign wealth fund model is not followed, is when the ACC reserves are more than \$20 billion above the outstanding claims liability.

What progressive realisation might look like

Chapter 3 sets out a roadmap to progressively realise the future system and discusses these options for expansion in more detail. This is intended to act as a starting point for discussion and to demonstrate that it is possible to develop a plan to move to the future system.

Recommendations for Principle 4: Planned Progressive Realisation

Recommendation 4.1

It is recommended that the Government task the Ministry for Disabled People to undertake the required consultation and policy development, and then prepare a roadmap to progressively realise this future system.

Expansion Principle 5: Healthier and Safer Communities

We must improve the health and safety of communities through creating an evidence-based system and a system for investment in communities.

If the vision is to be realised, then the future system must make our communities healthier and safer. The current system for improving the health and safety of our community is just as fragmented as the systems for supporting our people. The evidence (including data) that we are creating across our systems is focused on single causes, whereas most issues that arise for people and communities are multifactorial (more than one cause).

The numerous government agencies that have a focus on healthier and safer communities include the Police, Oranga Tamariki, ACC, the public health system, WorkSafe, the agencies regulating treatment, numerous commissioners including the Human Rights Commission, and the justice system. However, there currently is limited coordination across these agencies.⁴⁷ A proposal to develop a personal injury commissioner to oversee the personal injury system has been ignored by successive governments, but provides an example of how coordination could be implemented. There have recently been moves to do this in specific areas, for example the Joint Venture Family Violence and Sexual Violence.⁴⁸

No-fault and the return of fault

As we reflect back on the past five decades, we can see the reintroduction of fault. We no longer have a no-fault personal injury system. We have a limited fault system that compensates through the ACC system without fault, but then allows investigations by a series of agencies that look at statutory tests that are similar to the common law approach to negligence. These agencies sit within a fragmented regulatory system that fulfils functions in relation to education, accountability, and blame.

We have had a series of royal commissions that have resulted in the establishment of new organisations (for example the Health and Disability Commissioner, WorkSafe) and changes to criminal law. We currently have another one underway into Abuse in Care.

Each of these looks at specific circumstances. For example, when there is an issue arising at work, ACC provides treatment, compensation, and rehabilitation. WorkSafe is notified and decides whether to investigate and prosecute the employer. In many cases, the ACC investigation considers the role of the work or workers in the injury (or the illness) and if statutory criteria are not met, it does not provide cover. Whether a claim is accepted can influence premiums, which can lead to disputes in the ACC system about whether something is work related or not.

Often the injury or illness will have many causes. The worker may be tired, they may be distressed, they may have pre-existing health conditions, or be genetically predisposed to environmental factors. The systems we have and the data we generate through those systems do not allow for improvements in health and safety in our communities.

⁴⁷ Forster, Warren; Barraclough, Tom; Mijatov, Tiho "Solving The Problem: Causation, transparency and access to justice in New Zealand's personal injury system" [2017] NZLFRRp 10

⁴⁸ <https://violencefree.govt.nz/>

Previous research has recommended the development of a personal injury commissioner to look at how to coordinate and learn from the wider system.⁴⁹ The need for this collation of data and coordination continues.

Investing in communities to improve health and safety

The future system must create an evidence-based model for investment in communities. Connecting directly to communities to help them better understand issues and improve health and safety is likely to be the most effective way to do this.

Recommendations for Principle 5: Healthier and Safer Communities

Recommendation 5.1

It is recommended that the Government commit to improving the health and safety of communities by creating a cross-agency evidence-based system that invests in improving health and safety in communities.

Recommendation 5.2

It is recommended that Government mandate the collation of data through the various processes/agencies around factors that result in impairment and inequality based on cause of impairment or type of impairment.

Recommendation 5.3

It is recommended that the Government decides which organisation will be tasked with developing the framework for, and implementing, this evidence-based system.

Expansion Principle 6: Coordination with accessibility and discrimination prevention systems

We must provide oversight and coordination between this future system, the barrier identification and removal system (accessibility), the anti-discrimination system (Human Rights Commission) and the wider health and social systems.

A systemic approach must be adopted to remove disabling experiences. The three legislative models for enforceable rights, accessibility and non-discrimination must work together and must be coordinated. The options for this include one of the organisations administering one of the systems to be tasked with the wider coordination. For example, the Disability Commissioner in the Human Rights Commission has the function to promote and protect the

⁴⁹ Forster, Warren; Barraclough, Tom; Mijatov, Tiho "Solving The Problem: Causation, transparency and access to justice in New Zealand's personal injury system" [2017] NZLFRRp 10, Chapter 4 at 52.

full and equal enjoyment of human rights by persons with disabilities. It would be possible to expand this function to include wider systemic coordination to remove disabling experiences.

It must be recognised however that the legal jurisdiction of the Human Rights Commission's complaints process and the Human Rights Review Tribunal is limited to non-discrimination with all of its exceptions. The system is not set-up, designed and operating in a way to allow resolution of disputes about accessibility, or enforceable rights. Significant structural change, resourcing and legislative powers would be required for the Human Rights Commission to provide this coordination role.

Acknowledging this, another option is to either reform the Disability Rights Commissioner role or to create a new commissioner (or Authority) based on the Personal Injury Commissioner Model outlined in the report "Solving the Problem"⁵⁰. This model proposes a purpose-based approach,⁵¹ which can be adopted for this context. It would set the purpose of the commissioner to:

- enhance coordination between the institutions with functions and powers in relation to disability, including systems for enforceable rights, accessibility and non-discrimination; and
- facilitate durable system learning and feedback from the regulatory institutions into the management institutions to better manage the management institutions' relationship with individuals and prevent disputes; and
- improve access to justice and the being heard barrier by providing for system navigation and advocacy.

Other recent research recommended⁵² a process where people can notify someone about their disabling experiences. If this coordination system was to be developed, it could be adapted from that work to ask:

- What was the disabling experience?
- Was it caused by a barrier, a failure of the system of enforceable rights, or discrimination, or a combination of these?

⁵⁰ Forster, Warren; Barraclough, Tom; Mijatov, Tiho "Solving The Problem: Causation, transparency and access to justice in New Zealand's personal injury system" [2017] NZLFRRp 10.

⁵¹ Ibid, at 53.

⁵² Forster, Barraclough and Barnes *Making New Zealand Accessible: a design for effective accessibility legislation* [2021] NZLFRRp 8. A political decision was made not to follow this approach and the Accessibility for New Zealanders Bill was introduced into Parliament without any complaint, dispute, enforcement, or system learning mechanism.

- What accessibility standards or enforceable rights are in place (or in development) to remove this disabling experience?
- Is this disabling experience most efficiently and effectively removed by the development of new accessibility standards, the creation of new enforceable rights, an amendment to the non-discrimination system or by investing in healthier and safer communities?

Recommendations for Principle 6: Coordination with systems to remove disabling experiences

Recommendation 6.1

It is recommended that the Government commit to removing disabling experiences by tasking an organisation with identifying and coordinating the removal of them.

Recommendation 6.2

It is recommended that the Government decides which organisation will be tasked with this and resources that organisation appropriately.

List of all principles and recommendations

To assist in considering these recommendations as a whole and how they might work together, the complete list of the six principles and the associated 14 recommendations is set out below.

Principle 1: Te Tiriti and Human Rights Compliant

Recommendation 1.1:

It is recommended that the first principle of expansion is that the future system is designed to meet obligations under Te Tiriti and to provide the rights set out in international conventions, focusing on the Convention on the Rights of Persons with Disabilities, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the Declaration on the Rights of Indigenous Persons, and the Sustainable Development Goals.

Recommendation 1.2

It is recommended that the Government require the Ministry for Disabled People to comply with Recommendation 1.1 in all policy development.

Principle 2: Person-directed integrated system with person-centred dispute resolution

Recommendation 2.1

It is recommended that the Government commit to developing a person-directed system for people with impairments that is delivered through an integrated system of enforceable rights to social and income support, habilitation and healthcare with monitoring to ensure choice and control along with measurable outcomes for people.⁵³

Recommendation 2.2

It is recommended that the Government commit to implementing a person-centric dispute resolution model to allow people to enforce their rights under the future system.

Recommendation 2.3

It is recommended that the Government task the Ministry for Disabled People with the policy development to implement recommendations 2.1 and 2.2.

Principle 3: innovate the funding model

Recommendation 3.1

It is recommended that the Government commit to innovating the funding model to fund the provision of enforceable rights for people with impairments in order to provide long-term sustainability and equity for current and future generations through the future system.

Recommendation 3.2

It is recommended that the Government removes the outstanding claims liability from the ACC system, and transfers 80% to 90% of the ACC investment fund into an independent sovereign wealth fund planned for growth until the operationalisation of the future system.

Recommendation 3.3

It is recommended that the Government tasks the Ministry for Disabled people, in partnership with ACC and Treasury, to undertake the policy work in relation to the economic modelling for the future system, including the timeframes for expansion.

⁵³ Care must be taken to avoid the approach of blaming the person if the outcomes are not achieved in their individual case.

Principle 4: Planned Progressive Realisation

Recommendation 4.1

It is recommended that the Government task the Ministry for Disabled People to undertake the required consultation and policy development, and then prepare a roadmap to progressively realise this future system.

Principle 5: Healthier and Safer Communities

Recommendation 5.1

It is recommended that the Government **commit to improving the health and safety of communities** by creating a cross-agency evidence-based system that invests in improving health and safety in communities.

Recommendation 5.2

It is recommended that the Government **mandate the collation of data** through the various processes/agencies around factors that result in impairment and inequality based on cause of impairment or type of impairment.

Recommendation 5.3

It is recommended that the Government **decides which organisation** will be tasked with developing the framework for and implementing this evidence-based system.

Principle 6: Coordination with systems to remove disabling experiences

Recommendation 6.1

It is recommended that the Government **commit to removing disabling experiences** by tasking an organisation with identifying and co-ordinating the removal of them.

Recommendation 6.2

It is recommended that the Government **decides which organisation** will be tasked with this and resources that organisation appropriately.

CHAPTER 3: GETTING FROM HERE TO THERE

The purpose of this chapter of the report is to set out a possible plan to show how the future system can be implemented. It is accepted that there are different views on many of these points, however, this outline is provided to allow everyone involved, in particular disabled people and policymakers, to consider what they agree and disagree with, and to make an informed decision on whether they support this proposal as it stands, with amendments or not at all.

HOW WE MOVE FORWARD TOGETHER

Once an agreement has been reached on the vision, the enforceable rights of the future system, the six principles of expansion, and the fourteen recommendations, the task must be created for the Ministry for Disabled People to undertake the necessary work.

DEVELOP THE FRAMEWORK

Several tasks will be required in Year 1. These include the creation of the interim structure for expansion, the relationship-building process will begin, the economic and funding models must be developed, and the capacity and capability building work must start.

Task the Ministry for Disabled People to start the policy work for expansion (Year 1)

We must begin with a commitment to the vision, the principles of expansion and the recommendations, and this must include a ministerial responsibility for this. The recommendation is that the Ministry for Disabled People be tasked with building the infrastructure to bring this idea to life.

The immediate tasks of the Ministry are to start the consultation with stakeholders and to build the economic modelling. To do so, it will have to bring in multi-disciplinary expertise and be funded accordingly. This work will fail if it is not resourced, and it cannot be undertaken within the existing and currently proposed resourcing from the new ministry.

Build relationships with stakeholders (Year 1)

Effective relationships with stakeholders is the key to realising this future system. Consensus must be built to deliver the transformational change and the task of doing so lies with the Ministry for Disabled People. These key relationships include:

- Government Ministers
- Members of Parliament (including multi-party engagement)
- Existing institutional organisations inside and outside government (including ACC, health, social development, Whanau Ora)
- Disabled persons organisations
- Individuals and their family/communities
- Māori organisations and whānau/hapū/iwi
- Women's groups
- Business New Zealand
- Unions, including through the Council of Trade Unions.
- Relevant Commissioners, including the Disability Commissioner, Children's Commissioner, Retirement Commissioner.

Build the economic models to collect funds for the future system (Years 1-2)

Sovereign wealth fund

Develop and test ideas regarding funding models for the future system. The innovation proposed by the sovereign wealth fund is aimed to address the gap between economic growth and inflation in the costs of enforceable rights to provide sustainability.

The recommended approach here is to transfer 80 to 90%⁵⁴ of ACC funds into a perpetual sovereign wealth fund. There are undoubtedly different views, and it is important that the policy work to test different ideas with economists and others is done in a manner that is both transparent and robust.

If consensus is developed for the sovereign wealth fund model, then the legislation will need to be developed to move away from actuarial based funding (ie. calculating an outstanding claims liability).

The work needed here will be to decide on the structure of the sovereign wealth fund, whether it will be required to comply with the Santiago principles or an alternative ethical framework, and ensure system settings are set to maximise

⁵⁴ The exact amount to be taken must ensure that enough is left in the ACC fund to continue to function effectively if it were to face any financial shock.

growth of that fund over the coming decade. The simplest option is for the funds to be managed by the existing ACC team under the new structure as they have consistently outperformed benchmarks. The annual return on investment has averaged over 10%.⁵⁵

Consideration needs to be given as to whether a new levy is to be used to accelerate the growth of the fund. For example, instead of the new income insurance system, a lower levy of 2 to 2.5% could be used to accelerate the growth of the fund to the desired point for expansion within the desired timeframe.

Additional funding mechanisms

In addition to establishing the sovereign wealth fund, there is the need to decide how base-line funding will be collected. There is obviously a need to allow the funding collected through this method to increase with economic growth. This can either be done via a tax or a levy to provide the baseline growth in funding for the future system. If it is to be levied, the levy system will need to be developed along with settings for the funding model (what will be levied, when will it be levied etc).

Develop the economic and legislative infrastructure to allow these models to be used

The future system will require innovation in the funding models. Once the initial policy work is undertaken, the economic and legislative frameworks will need to be developed to implement this.

The alternative to the innovation of funding

If the sovereign wealth fund model is not considered appropriate, then other funding models could be considered. These include:

- a. Implement legislative requirements to increase funding
- b. Rely on multi-party political consensus to prioritise disability, health and social services.
- c. Borrow money each year to fund the provision of health and social services
- d. Increase taxes each year as required to fund the additional costs.
- e. Develop more and more complex rationing tools to control resource allocation
- f. Develop a private insurance model.

⁵⁵ See Appendix 4. ACC investment fund performance 1992 to 2021, Extracted from ACC's annual report 2021.

A brief discussion on these alternative approaches is included for completeness in Appendix 3. Some or all of these have been used in different parts of the health and social systems in New Zealand and overseas with limited effectiveness.

Build the data systems (Years 1 – 2)

For the future system to come to life, two important interrelated interoperable data systems must be developed. The first is to allow for the modelling of policy decisions on the expansion roadmap, and for the detailed policy setting that follow. The second is to allow for system learning and improvement in relation to the four enforceable rights and to meet the principles of expansion. As part of this process, trust has to be built with disabled people and communities. Some of this can be done through use of the Government's integrated data infrastructure.

An effective system for identifying and addressing systemic issues, including the use of complaints and dispute resolution, must be developed.

Build capacity (Years 1 – 10)

The capacity building must continue to gather pace. This is particularly important in three areas, leadership, co-governance and workforce. This must start now and continue throughout the expansion to the future system.

The leaders of the future system must be empowered and fostered now. Some of this work has begun within the disability community and disabled persons organisations. As part of this, a model for co-governance must be developed and implemented.

As the future system is developed, the workforce to operate and deliver the future system must be established, trained, and operationalised. Some of this workforce development work is already underway through initiatives led by New Zealand Disability Support Network. The models of workforce development should be replicated to ensure the future system has the required workforce. This capacity and capability-building work must be carefully planned in consultation with stakeholders and a whole of system approach must be taken.

Debate and plan the expansion roadmap (Years 2-4)

It must be acknowledged at the outset that there are many different options for the expansion roadmap. Having looked internationally and domestically, there are a number of approaches that can be grouped together into several themes. The first is by characteristics of the person, for example, things about their impairment, the cause of it, their age or where they live. The second is based on the type of enforceable right, for example healthcare, then social support,

then rehabilitation and then income support. The third is a funding-based approach based on choice where individuals or employers decide to join the system (a bit like the development of the KiwiSaver system). The fourth is an impact-based model taking a more agile and targeted approach based on a rights-based social investment model where the system is expanded to targeted groups. The final approach would be an economic conditions approach, where the system is expanded when certain economic conditions are met, for example when the return on investment on the sovereign wealth fund meets a certain percentage of the cost of the future system.

It is recommended that these approaches are the subject of wide consultation before the roadmap is determined. They have been detailed in a previous chapter but are set out here in order to allow consideration to be given to how these might be developed.

By impairment or person specific characteristics

There are several options for expansion based upon the person with the impairment. The first three are arbitrary criteria based on the impairment (level, cause, and type of impairment) and the final is the age of the person.

These create arbitrary lines which often result in disputes focused on the impairment, however they are widely used in nearly all comparable systems as rationing tools to ration who has access to the system. It is not suggested that these remain in place, but it would be possible to use these tools to allow the expansion of the future system.

(i) Level of impairment

Some schemes have been designed based on an assessment of a person's impairment to determine both entry into the scheme and what the person can receive as a result. These are either based on a medical or functional model of impairment. A likely disadvantage of this is the creation of disputes over the level of impairment and therefore entitlement. It may lead to the medical evidence issues seen in the ACC system.

It is possible to expand based upon the level of impairment. Such a model would allow policy decisions to be made setting the level at which entry to the scheme would begin, followed by a plan for broadening entry to the scheme over time. It could also allow this to be combined with other options, for example, widening the setting of who is in the existing scheme followed by progressive expansion of which enforceable rights people would receive once they are in the scheme.

(ii) Cause of impairment

This approach would allow coverage based upon the cause of a person's impairment. For example, all work-related impairment could be brought in at the same time. This would mean that it doesn't matter if the need is related to mental health, or cancer, if it is likely to be caused by work, it would be covered. There are a number of issues with this approach including proving causation. The current ACC system uses cause to ration services and support. Expansions based on cause would remove some of the current boundary issues, however, they would reappear over time around the new boundaries. People may also experience impairments with many different causes, and in many cases, more than one impairment.

(iii) Type of impairment

It is also possible to progressively realise the vision by expanding over time by type of impairment. This approach would see successive groups of impairments brought in over time. For example, congenital impairment could be brought in first, followed by mental health, then cancer and then diabetes. This approach would allow the benefits of integrated support to be seen as the system is expanded. The disadvantage of this approach is that many of our people experience more than one impairment, and the benefits of a person-centric system would not be seen until the expansion had been completed.

(iv) Age at diagnosis or assessment

Another approach would be to expand based upon arbitrary age criteria. For example, this could see the expansion start with young people under the age of 18, or with those over 65, or could start with the working age population (18-65 years). It could also allow certain support for those of working age (income support), and other support for people aged over 65 (social support). The significant advantage of age as an arbitrary criterion is that access to the system is not conditional upon a diagnosis and assessments of level of impairment, cause of impairment and type of impairment. This means that support and services can be accessed early. For example, a young person with neurodevelopmental impairment and their family/whānau would be able to obtain the support they need early on even before a diagnosis has been confirmed.

(iv) Geographic location

This could either be based upon location at time of development of impairment or at time of assessment.

These models allow expansion based upon geographic location. Coverage can be expanded region by region. The advantage of this approach would be that as people come into the system, they would immediately experience the benefits of integrated support and rehabilitation.

The disadvantages are that people will move homes to be within the transformed system, and the discrimination of the postcode lottery to access services will continue. This is the approach taken with the current disability support system and its various prototypes, pilots, and demonstrations.

By type of enforceable right (personalised social supports, income support, habilitation and healthcare)

This approach to expansion would see the system expanded nationwide for all people at the same time and would progressively bring each of the pillars of support and services under the future system. An example of this approach would be social support for all persons with impairments brought in first, followed by income support, then rehabilitation, and finally the health system.

The benefits would be seen quickly in each type of support. These could be provided without the need for diagnosis and assessment of level of impairment, type of impairment or cause of impairment. The disadvantage is that the benefits of integration would not be visible at a system level until the expansion had been completed.

If expansion would be possible over a short period of time (less than five years from 2025-2030) then this model of expansion would be possible providing there was acceptance that the benefits of integration would not be seen until expansion had occurred.

Individual choice or employer choice

The expansion of the system could be based on a voluntary scheme that is expanded over time. New Zealand's experience with KiwiSaver is an example of a system of development over time that started with small numbers and has expanded over time towards universal coverage. This has mainly been achieved with policy settings and incentives. The disadvantage with this approach is that many people living with impairments have lower participation in the labour market, so the discrimination that currently exists is more likely to continue (or could even be exacerbated) until the scheme moves through the voluntary phase towards more universal coverage. Some of the people who most need cover may never be able to participate in the labour market (non-earners and equivalent level of disability).

A rights-based social investment approach

This option is to follow a “social investment” approach to expansion. This offers an agile approach where decisions to expand can be made and tested based upon a social investment model. With the right human rights underpinnings ensuring access to justice is available, this approach could be used to develop a roadmap for expansion.

It is important that a social investment model looks at wider benefits to individuals and society, and not simply the narrow question of the cost to taxpayers.

Regardless of whether this is the favoured approach to expansion, robust modelling through the development of the data systems is critical to the transition to the future system and would be valuable in providing advice to Cabinet, the Minister and other decision makers.

When the economic conditions meet certain criteria

The final option is to trigger the expansion based upon the economic conditions which might be favourable to expansion. Examples of such criteria might be when GDP growth reaches a certain threshold, or the amount of money or return on investment from the sovereign wealth fund meets certain levels. For example, a decision could be made when the return on investment in the sovereign wealth fund is greater than \$10 billion per year or equivalent to 50% above GDP growth for three consecutive years. These are illustrative examples and should not be seen as an endorsement of this approach or a proposal to set these at specific criteria. These would need to be set following the economic modelling.

Determine policy settings (Year 2 – 4)

At the same time as debating the expansion roadmap, the options for policy settings will need to be developed to determine what will be provided by each enforceable right.

The work in relation to these policy settings should be undertaken by the Ministry for Disabled People, both initially and on an ongoing basis, following a process for initially determining policy settings and adjusting these over time.

It is critical that in considering and determining these policy settings, intersectionality of systemic discrimination and outcomes are at the forefront of policy makers minds. The policy team must include diverse perspectives beyond impairment and include considerations in relation to ethnicity, gender, and socio-economic status.

Policy Settings for Health

Below are some questions that will need to be considered when determining the policy settings for health:

(i) What time period should the provision of healthcare be for persons with impairments under this future system?

The healthcare requirements for persons with impairment should begin as soon as the impairment has been identified (even if it has not been diagnosed). This should continue for as long as the person has the impairment (and the future system must recognise that often this will be lifelong).

(ii) Once a person's healthcare is provided under this future system, what are the boundaries and limits (if any) of this healthcare?

The vision is that once the future system for impairment set out in this report has been realised, then consideration could be given to providing all healthcare under this type of model. In the meantime, all healthcare for persons with impairments should be provided under a single model to take into account multi-factorial causes and co-morbidities. This would not be limited to healthcare related to the impairment, but for all of the person's healthcare needs. It would also be possible to provide only specified disability-related healthcare only; however, this approach would lead to the disputes seen in the ACC system, further fragmentation of healthcare which is inconsistent with the principles for expansion, and cost-shifting. Therefore, this approach should be avoided.

(iii) How should the interactions between healthcare and social supports be designed in a way to reduce disabling experiences?

One of the challenges of the future system is the interface between a person's healthcare and their social support. There are a number of ways to define this boundary, and it must be worked through in a way that is seamless and person-centric at the point of delivery. Policy work will need to consider where this line is drawn. One example might be that healthcare includes any activity or "treatment" provided by or at the direction of a treatment provider, and if it is not, it is considered social support. It could also be defined by how the service is paid for, for example, whether it is paid for by the health component or the social supports component of the future system.

From the person's perspective, it makes no difference, provided the interaction between the health and social system doesn't create a disabling experience.

To ensure this doesn't occur, the future system must be codesigned in a way to avoid disabling experiences developing at the boundaries between systems.

(iv) Relationship between health under this future system and the wider health system

As is noted above at (ii), it must be acknowledged that one of the key questions to be considered is the relationship between the future system for health support for disabled people and the wider systems of health for all people in our society.

Regardless of the settings determined for health at the outset, for the reasons set out above, including the benefits of integration and the effect this has on the experience and health of people, over time the wider health system must be brought into the future system.

It is likely that this system for expansion will result in the setting for health in this system changing over time as the expansion is progressively realised. If there were a move towards a universal health insurance system or a hypothecated levy for health, then the future system must be designed to interact with the legacy elements of the existing system in a way that minimises boundary issues. Similarly, the timing of and the organisational structure for delivery must be carefully worked through. It could be that initially the healthcare for disabled people is included in the initial expansion and then at a later date, the wider healthcare system is brought in.

Ultimately, care must be taken to ensure that as the future system is realised all healthcare is included, otherwise the problems that are seen in the health system today will continue to develop.

Policy Setting for personalised social supports

In this report, personalised social support is used to refer to a wide range of personalised supports and accommodations that are provided by our society to help a person reduce their disabling experiences and to ensure their inclusion in our society. It could include personalised care, transportation, aids and appliances and anything else that is required long-term. The policy settings for this requires consideration of when social support should start, what levels it should be set at, and if and when it should end.

(i) When should social support start?

Personalised social supports and accommodations must start as soon as the impairment or need for support is identified or suspected. One of the key advantages that must be realised through the future system, is the provision of personalised supports and accommodations without the need for a formalised diagnosis or understanding of the cause of why a person needs the supports and accommodations. This system must be codesigned in a way that barriers to obtaining social support are entirely removed. There must be multiple entry points into the system and it must be fully accessible. The starting point for this is the Enabling Good Lives model that will be developed and expanded by the new Ministry for Disabled People.

(ii) What personalised supports and accommodations should be provided and at what levels?

Determining these settings will take significant policy work which is beyond the scope of this research project. It is recognised that this work will be difficult. What is required is a full understanding of the full range of personalised supports and accommodations for people with impairments that are not provided through other enforceable rights of the future system (ie. they are not classified as healthcare, income support or habilitation and rehabilitation). It must also be recognised that there are a number of options for service delivery including support packages of individualised funding. The model for service delivery will need to be determined later, the initial questions are:

- What is the scope of personalised supports and accommodations?
- What level will these be set at initially, and the process for reviewing these levels?
- How these will interface with healthcare and habilitation (see (iv) below)?

(iii) When should social support end for persons with impairments?

Social support must remain in place for as long as it is required. In many cases, it will be life-long. It can come and go as a person needs it and will change from time to time. Importantly, it doesn't diminish simply because time has passed, and unlike income support (which starts at working age, reduces as a person's earnings increase, and ends at retirement age), social support should remain in place long-term and will not diminish as a person's income increases. It makes no sense to transfer the cost of social supports and accommodations back to the person once they are working. Likewise, if supports are going to be provided in a person-directed and person-centred system, transferring social support costs to the traditional health system after a person reaches retirement

age (or providing these through the health system for anyone who develops an impairment after they reach retirement age) creates fragmentation.

(iv) Relationship between social support under this system and wider social supports

Most existing forms of social support will be provided under this single system. Care for people with impairments (regardless of cause) will be provided under this system. This must eventually include age-related impairment.

The only notable exception not included in this system is care for children (unrelated to impairment), and the related income support for paternal leave to care for children. An option for the future could be to provide childcare through social support but provide paternal leave through an expansion of the income support system. It could be that in decades to come; future policy development considers questions relating to transferring the costs of paternal leave from employers to a single system and what the outcomes of this might be. Ultimately, it is likely to improve the experiences and outcomes for birth parents to integrate the paternal support system with the proposed further system as is done in Scandinavia.

Policy Settings for income support

Income support would replace entitlements in the ACC system and benefits in the welfare system and the proposed income insurance system. This would be administered through a bureaucratic model of service delivery. There will be strict policy settings and limited discretion.

(i) When should income support start?

It is important that people do not experience sustained loss of all income. When income support starts requires a consideration of employers providing leave, the new proposed income insurance support model, and the existing ACC model for long-term income support. Also relevant is the various proposals for universal basic income or similar models. The way these existing and proposed systems interact must be developed and incorporated into the initial policy settings.

The current ACC system is dominated by minor injuries and short-term incapacity (a few weeks or less). One option to protect against this is to increase the period before the future system provides income support by several weeks or months, and either introduce a corresponding requirement to provide sick leave or develop an income insurance system that has now been proposed and pays short-term income support. After this initial time, the income support under

this system would begin, and the employer or social insurance system would no longer have to provide ongoing income support.

The impacts of extending the start date for income support would need to be carefully considered but limiting the impact on employers would reduce their risk and increase their willingness to provide employment for persons with impairments.

The system for income support should be available to all persons of working age. This could be set at an arbitrary age, for example at age 18, or in relation to the end of formal secondary education, when a person finishes or leaves school, or when a person is independent, for example, they leave home. Careful consideration must be given to different start points to ensure they provide the right support but also create the right incentives.

(ii) What levels should income support be set at?

There is an ongoing debate about the levels at which income support should be set. Currently, the ACC system sets this at 80% of a persons' earnings (up to a set maximum per week). On the other hand, people who can't work because of a non-ACC impairment have only limited income support set at less than 25% of the ACC maximum per week.

It is important that the minimum level of income support is set at a sufficient rate to bring all persons living with impairment out of poverty. This can be calculated as a percentage of the median wage or the living wage or similar, but it must be increased to reflect the labour market increases each year. This system should have an immediate effect on reducing the number of our people living in poverty. This should not be means tested and should not be reduced to reflect relationship status. If this type of system were to be implemented, it would significantly change the options and opportunities available to people and their families.

It is recommended that a parachute model be considered which would allow compensation to be set at a sufficient level to maintain financial commitments in the short to medium term (ie. for 6 to 12 months) after which the income support parachutes down over a set period of time until it reaches a set level (for example 125% of the median wage). Private insurance would continue to be available (as it is now) for those who wish to obtain high levels of income protection over the long term. Furthermore, fault-based systems such as WorkSafe and criminal law reparation could remain and will need to be improved to operate more effectively and efficiently following the approach set out above in the expansion principles at Chapter 2.

(iii) When should income support end?

Existing and proposed systems of income support often use time (set months or years) or assessments of work capacity or both to end income support. These models are unhelpful, create disputes and lead to significant negative disabling experiences. Instead, in the future system, income support should only reduce and/or end as a person's rehabilitation results in increasing personal earnings, or when a person's superannuation payments begin.

This will remove the medicalisation of the current processes and the fallacy that when a doctor says a person can work full-time, then the person can compete equally in the labour market and therefore is deemed to not require income support. This policy setting that exists in the ACC system has created system-wide cost-shifting from the ACC system to the social welfare system, and this is something that must not be repeated in any future system for removing disabling experiences. It is concerning that this same approach is proposed to be replicated in the new income insurance system.

Instead, the focus must be on an integrated approach of habilitation, social supports and income supports to rebuild social and financial capital. We must incentivise the operation of the system in such a way that it helps people actually get into work rather than be assessed as being able to work and then left to face barriers, stigma and discrimination in the labour market.

(v) Relationship between income support under this system and wider income support systems

It must be acknowledged that one of the key questions to be considered is the relationship between the future system for income support for disabled people and the wider systems of income support for people in our society. This includes people who lose their jobs or who reach retirement age and stop working. These must be carefully considered.

If the proposed income insurance system is developed, then the relationship between income support under this system and wider income support must be carefully considered. The proposed income insurance system could provide for a transition for people, but the current setting of that system will only provide short-term support and will only do this for people who are in work and then cannot work because of impairment. It will do little to help those of us with long-term impairments that continue to affect our work after the income insurance payments stop. It will do nothing for those people who are not in employment or are in limited employment.

Policy Settings for habilitation

Habilitation is a process of active change aimed at helping people gain, regain, or retain the skills, abilities, and knowledge they need to achieve their goals and remove disabling experiences. It involves things that help people to create change in their lives. It is person-directed and planned. It can stop, start, and change as required. It includes:

- processes aimed at increasing independence;
- specific tools that help people, for example assistive technology, aids and appliances; and
- the discovery process and customised employment in relation to paid and unpaid work.

Habilitation is different from social support, in that continues throughout a person's life, because habilitation starts and stops as required. It is different to healthcare which is focused on treatment. In the future system, the enforceable right to habilitation will begin at the minimum school leaving age⁵⁶ and continue for life.

(i) When should habilitation start?

In the future system, the enforceable right to habilitation will begin at a specified point in a person's life,⁵⁷ and continue alongside that person as they transition from the education system and continues for life. Habilitation must begin as soon as a person meets the age requirement or develops an impairment and must not be contingent on a person receiving a diagnosis.

(ii) What levels should habilitation be set at?

The aim of habilitation is to help people gain, regain, or retain the skills, abilities, and knowledge they need to achieve their goals and remove disabling experiences. Further work will be required to set the appropriate level for habilitation but there are already some key requirements. For example, we know that many disabled people face exclusion, particularly from work, with only 42.5 per cent of working-age disabled people compared with the 78.9 per cent of non-disabled people⁵⁸ aged 15 to 64 who were employed over the June quarter. The level of habilitation provided must allow for this disparity to be addressed. It must ensure people can increase independence. It must be coordinated with social supports and income supports to truly enable good lives and disabled people to thrive.

⁵⁶ Currently 16 years old, and in some circumstances, 15 years old.

⁵⁷ This point must be before the minimum school leaving age, currently 16 years old, and in some circumstances, 15 years old.

⁵⁸ Stats NZ, 17 August 2021, persons aged 15 to 64 who were employed over the June quarter of 2021.

(iii) When should habilitation end?

The enforceable right to habilitation should be lifelong. It can start and stop as required, but it will be available to people as and when it is required. It is essential that the policy setting for habilitation are designed to meet the principles for expansion included that it is person-directed.

(vi) Relationship between habilitation under this system and wider systems

Apart from the ACC system where the focus is on rehabilitation, resources for habilitation for disabled people are limited. This means that the future system can be developed with a limited need to integrate with existing systems for habilitation. Habilitation that works for people will empower people, but this alone will not result in inclusion unless wider legislative systems. It must however be coordinated with the accessibility system and the anti-discrimination system as there are significant barriers, and often discrimination, that prevents disabled people's inclusion in work and life.

Policy Settings for resolving disputes

It is inevitable that this future system will generate disputes. This should not be seen as a negative thing. A system for disputes provides an opportunity to resolve them, a process for people to be heard, and provides access to justice. From the system perspective, it creates opportunities for learning about systemic issues and to use these learnings for system improvement.

It is inevitable that adopting this type of human rights model for developing and implementing disability policy will present challenges. The right for people to challenge procedural or substantive aspects of this policy, and how it applies to them, is a fundamental part of the system.

It is recommended that this be broken into two sequential processes, the first focused on an informal justice approach through dispute resolution, and the second being a formal justice process involving courts.

It is essential that this system be designed in a way that system improvement and learnings are designed into the legislation, dispute, and court-based processes. Recent research has called for legislation to be developed in a way that it can be coded, and legal information is created and shared appropriately in the form of semi-structured data.⁵⁹ These innovations will make the law more accessible and perhaps more importantly from a system perspective, allow for improvement and dispute prevention and early resolution.

⁵⁹ Barraclough, Tom; Barnes, Curtis; Forster, Warren "*Judgments as data. Automated open-access analytics for decisions of courts and tribunals in New Zealand*" [2020] NZLFRRp 9.

The following is an outline of the proposed system to allow for development of the policy settings for resolving disputes:

i. A dispute resolution component

The dispute resolution system must be designed to achieve the highest attainable level of maturity when assessed against the nine standards and thirty-five key capabilities set out in the Government Centre for Dispute Resolution maturity framework.⁶⁰

Acknowledging that the first step in this process should be self-help through empowering people and their organisations, there must be an accessible navigation service to assist people. This must allow people to obtain any necessary expert assistance required to access the enforceable rights. This should be provided through an independent system of expert evidence.

The next step in this dispute resolution process must be a consensus-based dispute resolution model. It should not be compulsory, however, there should be a presumption towards an opportunity to use a process that is timely (within a few weeks) and designed to resolve issues and maintain or rebuild the relationships between people, organisations and service providers and allow people to enforce their rights. One of the leading examples in New Zealand of such a legislative system for dispute resolution is in the Tertiary Education Sector.⁶¹

ii. A legal court-type process

There must then be an independent tribunal established which provides an adjudicative process for resolving disputes that cannot be resolved through the consensus-based process (or which are not appropriate to be taken through that process). This could either be combined with the consensus-based model as a second step, as is the case in the tertiary education sector, or established as a Tribunal and administered by the Ministry of Justice and appropriately resourced to carry out its work.

iii. A right of appeal to the High Court on fact and law

The final substantive appeal must be to a court. The options are a specialist court,⁶² the District Court,⁶³ or the High Court. There are significant benefits of using the existing High Court process as it allows all aspects of a dispute to be determined together.

⁶⁰ <https://www.mbie.govt.nz/cross-government-functions/government-centre-for-dispute-resolution/dispute-resolution-tools-and-resources/aotearoa-best-practice-dispute-resolution-framework/>

⁶¹ Education (Domestic Tertiary Student Contract Dispute Resolution Scheme) Rules 2021.

⁶² For example, a model based on the Employment Court or the Environmental Court.

⁶³ For example, the process currently in existence in the ACC system.

iv. Leave-based appeals to the Court of Appeal & Supreme Court

The final step must allow legal questions to be determined. It is a fundamental requirement of the rule of law that questions of law can be determined by the Court of Appeal and Supreme Court. Having a leave requirement will allow the Court to determine when cases are appropriate.

Build infrastructure for improving health and safety of communities (Year 2 – 5)

The fifth principle of expansion is to improve the health and safety of our communities. As the future system is designed, the Government will need to:

- Create a cross-agency evidence-based system to invest in communities to improve health and safety
- Develop social licence around data, including the development of safeguards, before mandating the collection of data
- Task organisations with leading the development of the framework for, and implementation of, this evidence-based system.

Function

The core functions required to improve the health and safety of communities include learning from peoples' experiences, and then understanding what can be improved and how this can be done. The next step is then to develop a framework for improving health and safety and to implement this.

As part of this work, mechanisms must be developed to address accountability for organisations to improve the health and safety of communities. We must understand the myriad of organisations that currently exist and how these currently function. Further work must be done before deciding whether this would best be done by the existing multitude of separate agencies or whether there is a need to bring these together.

Institutional structures

A decision will need to be made on the structures for this. It is important that there is a relationship between the investment and the accountability system. They must operate independently of each other and share information with the data system in a way that meets expansion Principle 5.

Plan Transition of existing systems (Years 3 – 5)

Administrative model

Before the service delivery model can be finalised, decisions must be made about the administrative model for delivery of each of the enforceable rights. There must be a single administrative model, or alignment of the administrative models, for the four rights to ensure person-centric services. This design must be consistent with the six guiding principles of expansion.

By way of example, it would be possible for a single administrative system through an expanded Enabling Good Lives model or an ACC model (or an entirely new model) to provide income support directly, with funding for healthcare, social support, and habilitation services to be delivered by others.

Service delivery model

Once the process to determine the policy settings and the roadmap forward is underway, and consideration has begun of the administrative system, the options for service delivery will need to be considered and decisions made.

There are a number of options to do this, including those discussed above in the section on policy settings. It is beyond the scope of this work to set out how each of the services will be delivered. Consideration should be given to the six principles of expansion, the effectiveness of service delivery models, and choice and control for disabled people and how the enforceable rights of the future system will be given legal force and be enforceable by disabled people without barriers.

Transitional plan to transition current systems to future systems

It is recognised that Health NZ and the new Ministry for Disabled People have only just been launched on 1 July 2022. Both will be shaped over the coming years. At the point that the transition towards the future system is made, the Accessibility Legislation will also be in place. There will need to be a clear plan to transition all of these into a single structured system that meets the six principles for expansion.

Operationalise the future system (Years 5 – 10)

The final part of the planning required to get from here to there is to create the future system and operate it. By this point in the process, the planning work will have been done and the benefits of the future system will start to be realised.

At this point, we will have an integrated person-directed system for supporting people with impairments. This system will provide four enforceable rights to social support, income support, habilitation, and healthcare. Together with the complementary systems for improving accessibility and preventing discrimination, this system of enforceable rights will remove disabling experiences.

The vision set out at the beginning of this report will begin to be realised. We will start to see the benefits for disabled people. We will start to see the benefits for our economy, and we can consider the next steps as we look towards the future.

CONCLUSION

The ideas set out in this report are not new, but now is the time to breathe life into them and complete the work that began more than half a century ago.

This report opened with a vision; that in the future we will have an integrated person-directed system for supporting people with impairments that will reduce disabling experiences. This system will provide four enforceable rights to social and income support, habilitation, and healthcare. Failing to reach agreement on this vision will result in maintaining the status quo and further policy stagnation. This will entrench the inequality experienced by our people with impairment and maintain the disabling experiences for generations.

This report makes 14 recommendations and sets out a roadmap to achieve this vision within a decade. It explains how this future system of enforceable rights will interact with the accessibility system and the non-discrimination system so that negative disabling experiences can be progressively removed.

The response to those who say we can't afford this is that we can't afford not to do this. The response to those who say it's not possible, is that there is a clear pathway forward that shows that this is possible. This includes a way to develop and model the proposed system, its costs and benefits. There is a new Ministry for Disabled People that could be equipped and given the task to do this policy work.

At the end of Chapter 1, we were challenged to agree on: the vision for the future system, the four enforceable rights, the six guiding principles for expansion, the implementation of the 14 recommendations, and working together to develop a roadmap.

Some of us will find these easy to agree with. Others will find them more difficult as we don't yet know the details of how it would work. My challenge to you is to talk to your families, talk to your communities, talk to disabled people, talk to your colleagues. Let's see if we can get through these so we can work together to develop the roadmap to the future system.

This future system will help remove the disabling experiences, and together with the accessibility system and the non-discrimination system, it will really make a difference to the lives of Anna, Barry, Chantelle, Dave, Kane, Emily, Fi, Garry, Harry, Jay, Indie and the hundreds of thousands of disabled people that make up our communities

If we demand action, and if the recommendations are implemented, then we can create this future system, begin to realise this vision, begin removing disabling experiences and improve the lives of people for generations to come.

POSTSCRIPT

In early 2017, I drafted an application for a research fellowship and ultimately was privileged to receive this. At the time, the idea of expanding the ACC system/the future system was incomprehensible to many people, as the scale of reform required was perceived to be unrealistic.

To bring an integrated system to life when this work began, we needed to have consistency in the administration of the various systems that would fall under the future system (either a regional or central system), there was a need to either regionalise the health, social and ACC system or centralise the health system. We needed to have an entity (outside of ACC) to develop the policy and coordinate the systemic approach to allow the transformation. We needed to have an accessibility system to provide for the systemic approach to barrier identification and removal.

In the course of this research project, submissions have been made to the Welfare Advisory Working Group, the Tax Working Group, the health system review, the mental health system review, the Income Insurance system and to numerous other inquiries, committees and reviews.

Since then, the accessibility legislation has been announced, the health system has been reformed, the Ministry for Disabled People created, and now the income insurance system has been proposed. The ACC system will shortly reach its milestone of having more in reserve than its outstanding claims liabilities. I have spoken about this to too many people, presented at too many conferences, and written draft after draft of this report as these changes occurred. During this time, this report has been redrafted 120 times. The time has come to bring this work to a close.

What is missing from all the work being undertaken across the sector, is a vision for how this future system will work for **all** disabled people and a **plan developed** to bring this vision to life. If a principled based expansion does not occur, then in time, the gains that some people are celebrating now will continue to diminish, and the opportunity to develop and transition to the future system will be lost.

APPENDIX 1: DISCUSSION PAPER

A discussion paper was circulated with a link to an online survey.

DISCUSSION PAPER

Expansion of ACC

Working together to build a better, more equal health, social support, income support and rehabilitation system

We can work together to build a better, more equal system to improve our quality of life. A system that is person-centric that provides health, social support, income support and rehabilitation for everyone. Read our discussion and tell us what you think and share it with your friends and family.

Complete Our Caring Network

When we have an injury or impairment, we want to know we will get the care and support we need. Whether we experience an illness, accident or trauma we all want to be treated with dignity. We want to be supported to have the best life we can.

We want to know that those we love will be supported to continue to work, teach, communicate, care for others, find happiness and thrive in our communities.

A sustainable system

We need support from people in Government so we can improve the quality of life for New Zealanders in the long term and improve the situation for people who currently feel trapped and hurt by the system. To do this we need a caring and inclusive disability system designed to serve all people, regardless of impairment. A system shaped around our people and our future wellbeing.

Right now, this isn't the case for everyone in Aotearoa. Our loved ones get different levels of care and support depending on how their impairments were caused. We have different systems: ACC and everything else, which lead to very different outcomes for our people. This is not fair, and it's not how it was intended to work. Right now, we have a chance to change that, to bring the original idea to life and build a fairer system that we can all depend on.

So how did we get here?

The system we have is incomplete and it is causing harm

It works for some people, but not for others. People receive different standards of care. This includes different treatment, rehabilitation and income support based on how they got their injury or impairment. Families are expected to pick up what people in government choose not to provide. This was not how our system was supposed to work.

In New Zealand in 1967, the Royal Commission suggested a ground-breaking approach: a social insurance scheme to care for people with impairment. No matter how someone got an impairment, how old they were or whether they were working, they would receive ongoing care and support from a single system.

Until now, people in government have chosen not to follow this plan. Over the years our leaders have chosen a two-tiered system. High quality care and support is available to people who experience impairment and disability through an accident. Others are left to struggle in systems not set up for their needs.

Our system is like a city with an unfinished transport network. In this city, people in some parts of the network can't go where they need to. There are no footpaths, roads, taxis, bus routes or cycle lanes, for them and bus routes or roads weren't built near their homes. Others have infrastructure built to their front door and any vehicle they need. It means some people can get to where they want, while others, for reasons out of their control, are stuck. They cannot travel anywhere at all.

Our unfinished network impacts people and families

Too many people are dealing with a substandard, unkind, even harmful system. This experience comes because their impairment was present at birth, caused by cancer or depression, or their claim with ACC was declined. It does not make sense to separate these systems. This unfinished network pushes people into stressful experiences between various systems that can harm them. We can change this network. We can maximise health for all people. We can minimise the stressful experiences coming from our incomplete and fragmented support system.

Case Study 1 - James

James had a motorbike accident at 28. He lost his right leg above the knee and cannot use a prosthetic limb. He uses a wheelchair. He also lost his spleen which makes him prone to infections and has a brain injury which makes it difficult for him to concentrate for long periods of time. James was an engineer before his accident. He couldn't safely continue this work.

ACC supported changes to James' house. He receives income support

that covers the mortgage. This continues indefinitely until he can return to work after his retraining (which is also funded by ACC). James received a large payment in compensation for his impairment. He used it to travel overseas on holiday for two months with his girlfriend. After all, they had been through some stressful times.

Any time James needs to access healthcare, he simply phones his case manager. It is paid for by ACC using the private healthcare system.

Case Study 2 - Sam

Sam was born with a disability. She requires full-time care. Doctors and lawyers disagree about whether the hospital contributed to Sam's impairments. It has taken six years and the dispute about whether people in Government should provide support has still not been resolved. In the meantime, without access to support Sam's family had to provide the support. Sam's mother quit her job to ensure she could care for her young daughter. She receives no recognition for the work she does to care for Sam. The government decided it does not need to help parents because it is "natural" that parents care for their children.

Sam's parents were saving for a house, but they used all their savings to cover the costs required to keep Sam well. They have run out of money. Sam's situation won't improve, and her parents are only getting older.

Sam's mother is dedicated to her daughter. She became very unwell, and experiences psychosocial disability herself. She finds dealing with a complex system very stressful and almost a full-time job itself. Sam's father took on another job to try and cover Sam and her Mum's support costs. He is always tired. This affects him at work and at home.

The family went from financial security to poverty. Supporting Sam can be difficult but dealing with the system makes things worse. It's stressful, and Sam's parents have struggled with their relationship. They just need a break. Her parents know about experiences and treatments that Sam could have had. She has missed out even though these could have improved her quality of life.

Case Study 3 – Jill

Jill is a teacher. She became ill in her 30's, and a diagnosis of breast cancer was initially missed by her doctor. She was eventually diagnosed at 40, treated and is now in remission at age 45. The serious side effects of her treatment and of the cancer means she is no longer able to work. She is vulnerable to infections. Jill lived alone and had no other family to help care for her or support her financially. She

APPENDIX 1

was forced to sell her house as she could not afford the mortgage payments. Her rate of income support is similar to the unemployment benefit. She is now forced to move between damp rental properties, vulnerable to infections and illness, and unable to do the best to care for her health.

Jill is in and out of hospital all the time. She experiences significant mental distress at her loss of her career, financial wellbeing and health. If Jill needs help to pay for treatments or rehabilitation, she has to go to various different agencies. Jill's case has been in Court for five years. People in government have been arguing they should not have to pay for Jill's care for all this time.

Some case workers at the government agencies show little respect for Jill, treating her as if she is trying to game the different systems for ongoing support. Jill is scared to meet new people socially because her support payments could be reduced if the government decides she is in a new relationship. This just adds to her stress, her lack of support, and loneliness.

What can we learn from these case studies?

We know that impairments can be present from when we are born, or they can appear during our lives when we are injured or ill or have impairments that happen gradually like hearing loss or vision impairment. As we get older, many of us will also develop age-related impairments. If our Government does not have good accessible ways of providing assistance through good systems, then these people will experience disability. Also, the systems we have now cause lots of disputes, for example when ACC decide people have a "pre-existing degenerative condition".

It doesn't have to be this way. As New Zealanders, we can decide how we want our system to work and then we can demand that the people in Government make the system the way we need it.

It is time to complete the support network and improve people's lives

We can complete this unfinished system. People in our government created it and it does not have to be this way. A growing group of people across the political spectrum have raised concerns about the issues caused by our current system. We all know somebody dealing with this system. Reviews have been happening across New Zealand's health and social policy systems because people living and working in those systems have called for them. The people in Government have signalled a desire for services that are kinder and fairer, focussed on ensuring our people are healthy and safe, that has our collective wellbeing at its heart.

Now is the time to act. This is an idea whose time has come.

This is our chance to improve the way our society cares. By providing appropriate rehabilitation, income support, and assistance for those with injuries and impairments we can reduce the disability experienced by people in our society. We can make things healthier and safer in our communities. Where appropriate, we can improve prevention efforts and improve the quality of life for people with impairments and the people who care for them.

The evidence and modelling shows that it is possible to build an effective and integrated network. Over the long term, we can have a society that includes everybody, through paid work, caring for others, education and support, creating and experiencing happiness. That is undeniably better for all of us.

People in government have created a system that discriminates. As a result, we waste too much time and money on assessments and disputes about what caused an impairment and who should pay for support. People just want to get on with their lives, but the system will not allow this to happen.

We all want to live in a society where people are healthy, safe and part of a community. We want to treat each other with compassion. We want to help each other.

What can you do?

What do we need to do? We need to build agreement. We'll need Government support to build this system. We need the Ministers for ACC (Hon Iain Lees-Galloway), Health (Hon David Clark) and Social Development & Disability (Hon Carmel Sepuloni) and politicians from all parties to take up this matter on behalf of all New Zealanders. Politicians need to know that we care about this. They also need to know your ideas about how to make it work.

You can let them know what matters to you. Politicians often do not lead. They listen to the public before they act.

What do you think?

Complete a quick survey so that we know what you think. It will only take a few minutes and the results will be shared with people in government who want to know what the public thinks about this idea.

APPENDIX 2: OVERVIEW OF RESPONSES

The Survey was broken into two parts. The first part of Survey was open text: there were two open text questions to allow a thematic analysis of what was important to people. These questions could be skipped. The second part of the survey posed four questions that were designed to understand what people wanted the government to do and why.

First Part of Survey

How the Government treats and responds to people who did or did not have an accident

Accident: Think about people who have an impairment or disability that DID result from an accident (eg. they had a fall at home). What is important to you about the way people in government treat and respond to people in such circumstances? (n=679)

Non-accident: Think about people who have an impairment or disability that DID NOT result from an accident (eg. they have cancer, long term depression, were born with impairments, or have a chronic illness). What is important to you about the way people in government treat and respond to people in such circumstances? (n=735)

Responses to first part of the survey

The responses were skipped by some people, but the themes were that people want care, support, income support, fairness, equity, transparency, trust, community connection, a system that works for them. They don't want to live in poverty, they want to have improved social and financial capital. They want an integrated, person-directed system to deliver this.

People are not satisfied with the fragmented system, and they want the government to fix this. They want healthier communities and safer communities.

Second part of Survey

What should the government do, how should they do it, what are the barriers to a single system and what are the benefits?

WHAT DO YOU WANT PEOPLE IN GOVERNMENT TO DO?

What should the government provide?

Thinking about people who have an impairment or disability that did not result from an accident (eg, they have cancer, long term depression, were born with impairment or have a chronic illness). What should people in government provide in such circumstances?

Don't change anything - the current system is enough (2.71%, n=23)

The same as people who have accidents (79.60%, n=675)

More for non-accident than accident (11.56%, n=98)

Something else (please specify) (31.60%, n=268)

How should the people in government provide this?

Do you think people in the government should:

Create a single integrated system for impairment and disability support for everyone where it doesn't matter how a person's impairment began. (79.98%, n =679)

Continue with the current separate systems of different impairment and disability support depending on whether the impairments were caused by accident or non-accidents? (8.24%, n=70)

Do something else (please explain what and give reasons why) (22%, n = 188)

THE BARRIERS

What do you think are the main barriers to building a single integrated system? (you can choose more than one)

Working out how to fund the single integrated system (45.91%, n=387)

Knowing if the single integrated system was working (21.95%, n=185)

I do not think there are any barriers significant enough to stop us building a single system (46.86%, n=395)

Other barriers exist or would be created by the new system (please specify other barriers) (30.13%, n=254)

THE BENEFITS

What do you think are the main benefits of building a single integrated system?

A single system would be more effective (49.47%, n=419)

A single system would be more efficient (50.65%, n=429)

A single system would improve dignity for people (65.76%, n=557)

A single system would be fairer and more equitable (76.62%, n=649)

A single system would improve people's experiences (53.72%, n=455)

I see no benefits of having a single system (7.67%, n=65)

Something else (please specify) (19.13%, n=162)

APPENDIX 3: Further details of funding options

Further discussion of Expansion principle 3: Innovation of the funding model

Why is innovation necessary?

Until now, with the exception of those covered by the ACC system, all publicly available services for people with impairments have been funded by taxation. Increases in tax are tied to economic growth. When the costs of providing what people need increases faster than tax revenue from economic growth, there is not enough money to cover the increasing costs. Because there is not enough money, the perception of people in Government is that the only option is to limit what people can get. This results in more and more complex measures to rationing tools. These are the source of significant disabling experiences. This has been the experience of disabled people interacting with almost all of the government systems for helping disabled people.

The notable exception to that has been the ACC system. The entitlements provided by ACC that are the equivalent of the four enforceable rights have increased at an average of 8.6% per year over the past nine years. The economy during this time has grown by an average of 3.1% per year.

Table 2: Annual growth in ACC funding for future system costs compared to GDP growth

Year (1 Jul - 30 Jun)	Cost of four enforceable rights ⁶⁴ (\$ billions)	Annual Growth	GDP growth ⁶⁵
2012/2013	2.681		2.30%
2013/2014	2.947	9.92%	2.70%
2014/2015	3.211	8.96%	4.10%
2015/2016	3.488	8.63%	3.80%
2016/2017	3.676	5.39%	3.60%
2017/2018	3.974	8.11%	3.60%
2018/2019	4.336	9.11%	3.10%
2019/2020	4.597	6.02%	-1.00%
2020/2021	5.179	12.66%	5.20%

⁶⁴ Taken from ACC Annual Reports 2012 to 2020.

⁶⁵ Taken from Stats New Zealand < <https://www.stats.govt.nz/indicators/gross-domestic-product-gdp>>

Innovation in the ACC funding model

In the 1990s, political consensus was developed to “fully fund” the ACC system. The idea was to move from a system which collected levies this year to meet this year’s costs to a system which collected levies this year to pay the lifetime costs of all injuries that occurred this year.

Issues have arisen around the outstanding claims liability, for example interest rate changes have a large effect on how much money is needed to fully fund the outstanding claims liability and this can cause problems with the delivery of services in particular years. As a result of these problems, the ACC system can swing like a pendulum between being generous and expansive and being mean-spirited and limited. These swings have terrible experiences for our people.

Table 3: Annual return on investment

Year	Financial position at 30 June	Net return on investment	Income from return on investment (\$ billions)	Costs of four proposed enforceable rights	Shortfall of investment income to costs of enforceable rights
2011/2012	20.4	-	-	-	-
2012/2013	24.909	9.80%	\$2.00	\$2.68	-\$0.68
2013/2014	27.588	6.33%	\$1.58	\$2.95	-1.3702603
2014/2015	31.83	14.43%	\$3.98	\$3.21	0.7699484
2015/2016	34.8	10.22%	\$3.25	\$3.49	-0.234974
2016/2017	36.6	5.70%	\$1.98	\$3.68	-1.6924
2017/2018	39.6	9.80%	\$3.59	\$3.97	-0.3872
2018/2019	43.8	12.97%	\$5.14	\$4.34	0.80012
2019/2020	47	7.60%	\$3.33	\$4.60	-1.2682
2020/2021	50.3	10.40%	\$4.89	\$5.18	-0.291

The alternative to innovation of funding

If the sovereign wealth fund model is not considered appropriate, then other funding models could be considered. These include:

- Implement legislative requirements to increase funding
- Rely on political consensus to prioritise disability, health, and social services.
- The Government borrows money each year to fund the provision of health and social services
- Increase taxes each year as required to fund the additional costs.

- Develop more and more complex rationing tools to control resource allocation
- Develop a private insurance model.

These and the reasons they are not proposed here will be briefly discussed. These are not intended to be exhaustive but instead illustrative of how each might work.

(i) Legislative requirements set out increase formula using current system

This was the recommendation from the Health and Disability System review in 2020.⁶⁶ It framed the funding issues as efficiency and effectiveness. This review recommended an annualised increase taking into account:

- total population and changes in population demographics (eg. age and ethnicity)
- costs of products and services
- costs of wages.

With respect to the expertise of the review members, there is only so far that efficiency and effectiveness will go and ultimately this will hit problems with its reliance on tax. A legislative approach may change the priority given to increasing funding from taxation by successive Governments to the health and social system, but this is unlikely to be effective in the long-term. Effectiveness and efficiency gains will only go so far, and once the legislated increase model starts lagging behind, the provision of services will continue to be rationed and the cost will once again be shifted back to families and communities. What will occur over time is that more and more complex rationing tools will be developed and integration of health and social services will come under pressure, and it will be replaced with boundary disputes and cost shifting between systems. The other risk to this approach is that in times of recession where tax income decreases, it will be difficult to meet the legislative requirements.

(ii) Political consensus

Multi-party political consensus on the vision would be helpful. It is required for debate on the roadmap forward. However, international experience has shown that political consensus alone is not enough to provide long-term sustainability. In the short term, it can produce momentum for reform during periods of economic growth where political consensus can achieve moderate stability. In the medium term, political consensus will help smooth out bumps. However, in a recession, political consensus to prioritise funding for disability/health/social services cannot meet the rising costs as tax revenue is simply not available. When this occurs, political consensus to prioritise funding will fail to allow

⁶⁶ Health and Disability System Review 2020, Final report, p 58.

sustainable services and unless money is borrowed, rationing tools are likely to be used to ration who gets what help.

(iii) Borrow money to fund health and social services

Another option that is available to Government is to borrow money to spend on health and social services. There is no particular reason not to follow this approach, particularly if it is used to underpin an investment actuarial basis for decision making. It must be remembered however that money borrowed must be repaid.

(iv) Change tax system so more tax is collected each year as required to fund the additional costs

An option that has not been commonly used in New Zealand is to change the way we tax income, profits, or capital gains. For this to be effective in the long run in solving the problem two things would need to occur. There would need to be an increase in tax income to cover the gap between economic growth and inflation in the health and social services. Second, there would need to be a commitment through political consensus or legislation for this increased tax income to be used for health and social services.

(v) More and more complex rationing tools

There is a consistent experience internationally with rationing tools being used to constrain the provision of health and social services. Over time, these tools are becoming more complex and more costly to deliver. An example here is the causation tests within the ACC system that require ACC staff to obtain evidence to address complex statutory tests before decisions can be made on cover and entitlements. The costs of administering the ACC system now range between \$500 million and \$700 million per annum. The health system and the social system also have significant costs of assessment and administration. The total cost of annual costs of administration/rationing tools across the ACC, health, social and disability system is estimated at between \$1.5 billion and \$3 billion. By having a person-centric system without the administrative boundaries, a significant portion of this cost could be saved and instead spent on support/services for people.

There are many examples where the cost of determining cover and entitlements is more than the entitlements provided. The resulting decision by ACC to streamline the process to approve the cheaper claims has resulted in widespread gaming of the claims process.

The development and implementation of rationing tools in other areas of New Zealand health and social setting can be seen in the claims data. Whilst the number of work and motor vehicle injuries has increased faster than population growth, the number of home injuries increased more than forty-nine times

during that 25-year period. Today, more than 40% of New Zealanders lodge a claim for personal injury each year.

(vi) Private insurance for individuals/families

The final alternative would see a move towards private insurance. This would either be provided by an employer or purchased by individuals. The growth of insurance would be unlikely to reduce inequality and fairness in New Zealand's society as those with impairments would face barriers to entry and higher premiums to continue to access support and services as is seen in the United States. This this is clearly not compliant with aims of UNCRPD.

**APPENDIX 4: PERFORMANCE OF ACC INVESTMENT
FUND 1992 – 2021 (ACC 2021 Annual Report)**

Investment performance – long term

10.07%

RETURN SINCE 1992

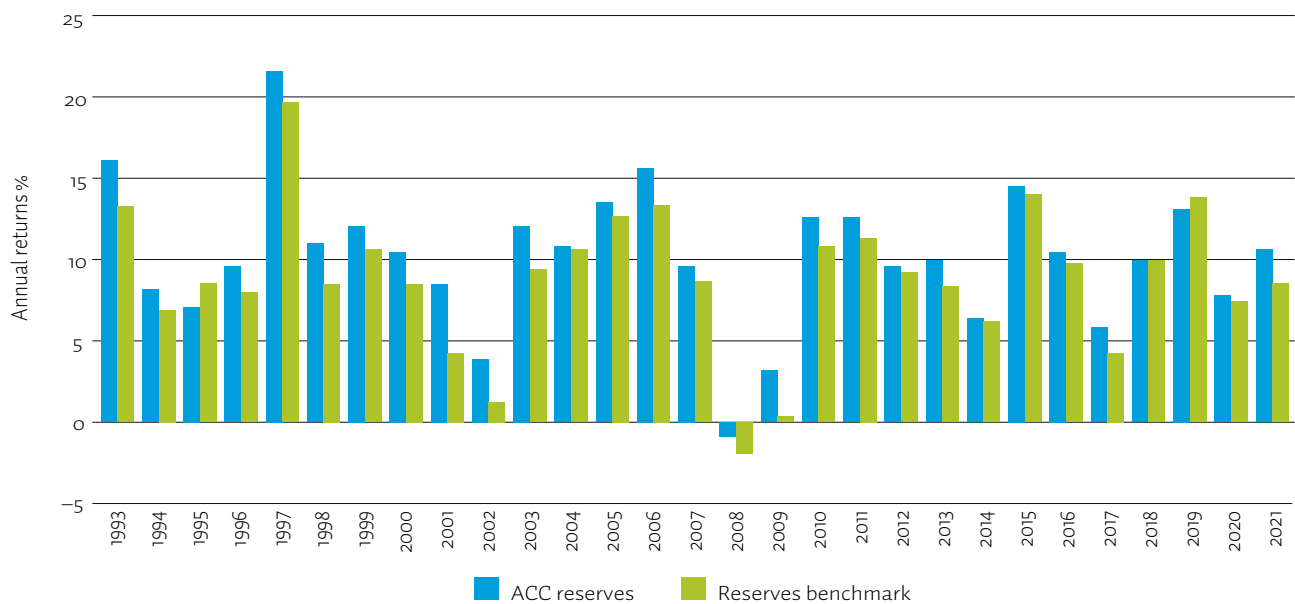
\$1,615

GROWTH OF \$100 SINCE 1992

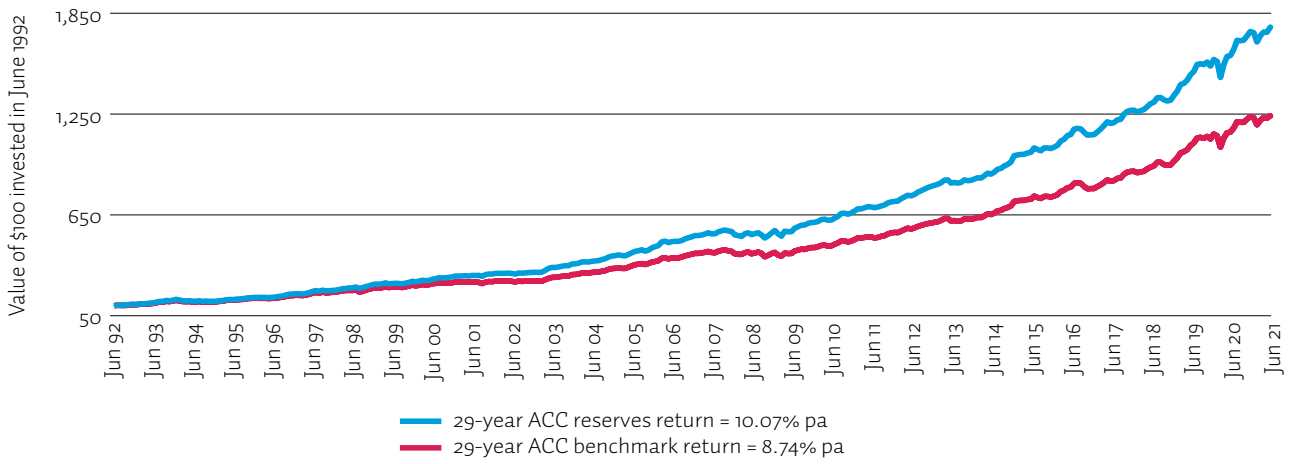
The investment portfolio has outperformed its benchmark for 27 of the past 29 years. ACC’s consistent outperformance has been achieved by a unique group of highly dedicated and specialist individuals.

The consistency of ACC’s historical investment performance has helped ACC to achieve compound returns from the reserves portfolio of more than 10% per annum for the past 29 years, which is higher than ACC could have achieved by passively investing in any of ACC’s benchmark indices.

GRAPH 11: ACC FINANCIAL YEAR RETURNS AGAINST BENCHMARK

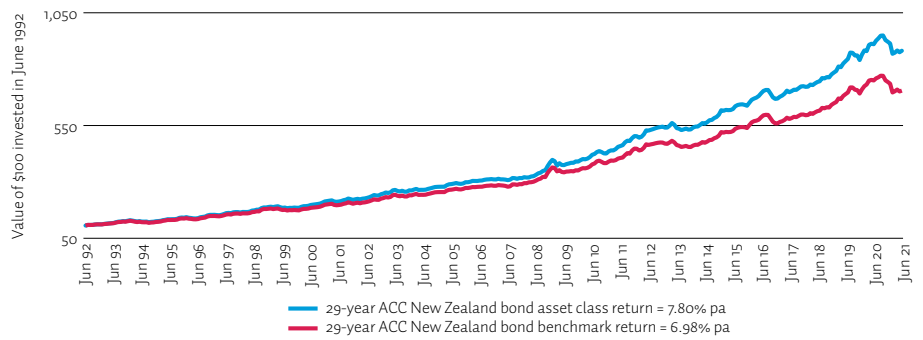


GRAPH 12: ACC 29-YEAR RESERVE PORTFOLIO RETURNS



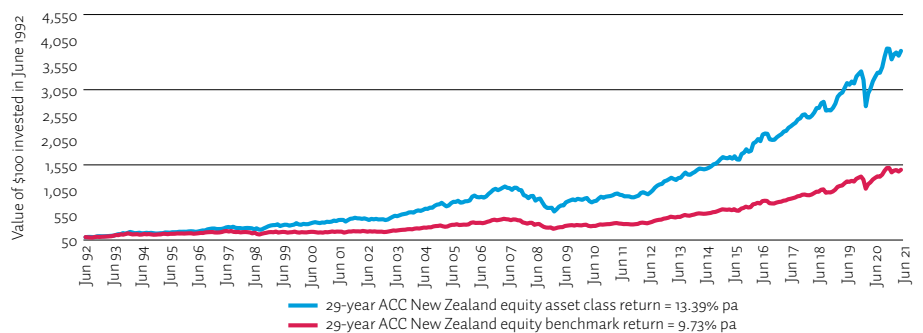
The **New Zealand bond** portfolio has outperformed its benchmark in 27 of the past 29 years.

GRAPH 13: ACC 29-YEAR NEW ZEALAND BOND RETURNS



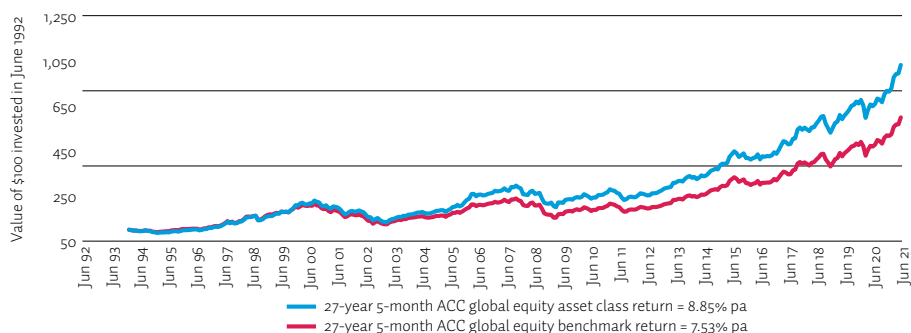
The **New Zealand equity** asset class has outperformed its benchmarks in 23 of the past 29 years.

GRAPH 14: ACC 29-YEAR NEW ZEALAND EQUITY RETURNS



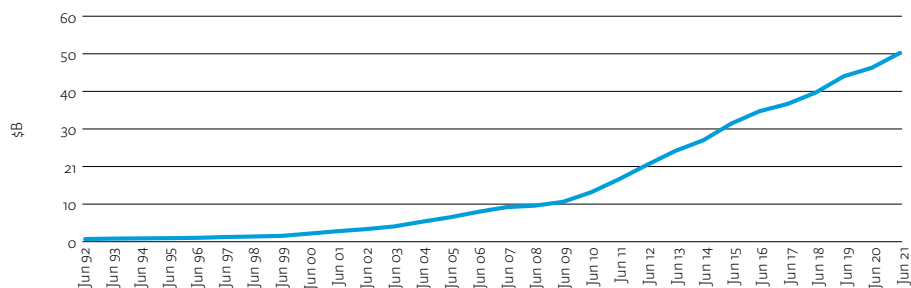
The **global equity** asset class has outperformed its benchmarks in 19 of the past 27 years.

GRAPH 15: ACC 27-YEAR 5-MONTH GLOBAL EQUITY RETURNS



ACC’s reserves portfolio has increased in value by 8.54% from \$46.2 billion last year to \$50.19 billion at the end of June 2021. The growth is the net impact of investment returns, offset by withdrawals (\$910 million) for operational cash-flow needs.

GRAPH 16: VALUE OF ACC’S RESERVE PORTFOLIO (\$ BILLION)



Please note: For the purpose of this graph, traded investments and performance are valued at last sale price (or at valuation, in the case of unlisted investments).

Investments returns

Future investment returns

We expect future returns to average around half of what has been achieved historically (ie less than 5% per annum rather than the 10% historically achieved). This is because interest rates are now at low levels, and other investment assets such as equities are starting from high valuation levels.

The likelihood of negative returns

ACC has had only one instance of a negative overall investment return in the past 29 financial years. However, for the same reasons that we expect future investment returns to be lower than historically, the likelihood of negative returns has increased. With lower expected investment returns from fixed-interest assets, there is now less of an income buffer to absorb negative shocks. Going forward, we expect a negative return about once in every three years.

The two primary factors that drive the risk of negative returns are:

- a rise in bond yields. However, ACC's overall financial position would improve as a result, as the claims liability would decrease by an even greater amount than the decline in investment returns
- a general decline in foreign and domestic equity prices. Using current allocations for ACC as a whole, a decline of around 3.5%, over a financial year, would be far enough below our current expectations to offset the expected returns from other assets.