### **Hon Carmel Sepuloni**

### MP for Kelston

Minister for Social Development Minister for Disability Issues

Associate Minister for Arts, Culture and Heritage Associate Minister for Pacific Peoples



Ms Katrina Bevan fyi-request-8362-42f0cdc2@requests.fyi.org.nz 2 N SEP 2018

### Tēnā koe Ms Bevan

On 20 July 2018, you emailed my office requesting, under the Official Information Act 1982, documents that inform my decision making in disability-related issues, and information on disability issues monitoring mechanisms.

As the Minister for Disability Issues, I am responsible for advocating across government on behalf of disabled New Zealanders, and ensuring government services and policy consider their needs and interests. The framework for achieving this is the New Zealand Disability Strategy, with the vision of New Zealand as a non-disabling society - a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen. Further information and a copy of the Strategy is available online at www.odi.govt.nz/nz-disability-strategy/.

Please note that while I and my fellow Ministers decide both the direction and priorities of our departments, we are not generally involved in day to day operational matters, such as making decisions for individuals.

When I took on the Disability Issues portfolio I was provided with a high-level overview of its scope, opportunities and priorities in a Briefing to the Incoming Minister, which is available online at www.msd.govt.nz/documents/about-msd-andour-work/publications-resources/corporate/bims/2017/disabilities-bim-2017.pdf.

In the months that followed, I was provided with additional documents which outlined the disability-related mechanisms, supports and processes as well as the impediments faced. Please find attached the following documents:

- 'Key Disability-related mechanisms, support and processes', dated 13 November 2017
- 'Report on the New Zealand Disability Strategy 2016 2026', dated 13 November 2017
- 'Disability data', dated 20 December 2017.

Appendix 2 of the document 'Key Disability-related mechanisms, support and processes', dated 13 November 2017, provides information on the groups and processes who ensure cross-government leadership, accountability and coordination on disability issues. Of particular interest to you may be the Independent Monitoring Mechanism, which provides an independent view of New Zealand's implementation of the United Nations Convention on the Rights of Persons with Disabilities. A group of Ministers meet with this independent body on a regular basis to report on progress on disability-related work.





You will note that the names of some individuals are withheld under section 9(2)(a) of the Act in order to protect the privacy of natural persons. The need to protect the privacy of these individuals outweighs any public interest in this information.

Some information is withheld under section 9(2)(g)(i) of the Act to protect the effective conduct of public affairs through the free and frank expression of opinions. I believe the greater public interest is in the ability of individuals to express opinions in the course of their duty.

Some information is withheld under section 9(2)(f)(iv) of the Official Information Act as it is under active consideration. The release of this information is likely to prejudice the ability of government to consider advice and the wider public interest of effective government would not be served.

Some information is refused under section 18(d) of the Official Information Act on the basis that the information requested will soon be publicly available. This information will be published as soon as possible this year.

If you have further concerns specifically about education, you may wish to write to Hon Tracey Martin, Associate Minister of Education.

If you are not satisfied with this response regarding my decision making in disability-related issues, and information on disability issues monitoring mechanisms, you have the right to seek an investigation and review by the Ombudsman. Information about how to make a complaint is available at <a href="https://www.ombudsman.parliament.nz">www.ombudsman.parliament.nz</a> or 0800 802 602.

Ngā mihi nui

Hon Carmel Sepuloni

Minister for Disability Issues



### Report

Date:

13 November 2017

Security Level: IN CONFIDENCE

To:

Hon Carmel Sepuloni, Minister for Disability Issues

### Key disability-related mechanisms, support and processes

### **Purpose and summary**

- This report provides advice on how you and relevant colleague Ministers might engage with the Independent Monitoring Mechanism (IMM). Background information is provided on previous engagement between the IMM and Minister(s).
- The Office for Disability Issues proposes that the New Zealand Disability Strategy provides the context and purpose for engaging with colleague Ministers and the IMM to realise better outcomes for disabled people.
- 3 There is important and aligned disability-related work across other portfolios:
  - the transformation of the disability support system work programme led by the Ministry of Health
  - the Ministry of Education's Learning Support" work programme and
  - the Disability Confident campaign led by the Ministry of Social Development
- 4 In the appendices we provide a response to your request for information on:
  - advisory groups supporting the Office for Disability Issues and other disability projects (including membership)
  - disability-specific funding across portfolios
- The Briefing for Incoming Minister for Disability Issues (BIM) and a briefing on the New Zealand Disability Strategy provide more detailed information on strategic opportunities in the Disability Issues portfolio and other portfolios.

### **Recommended actions**

It is recommended that you:

1 **Note** for discussion at the next agency meeting disability-related priorities and possible opportunities for change in the engagement with Ministers.

Brian Coffey Director

Office for Disability Issues

Date

Dat

Hon Carmel Sepuloni

Minister for Disability Issues

### The New Zealand Disability Strategy is a framework for progressing disability issues across government and with the Independent Monitoring Mechanism (IMM)

- Over 2016, the Office for Disability Issues led a widespread engagement with disabled people, their families and the wider disability sector to find out what was most important to them.
- The disabled community's views were needed to revise the 2001 New Zealand Disability Strategy, which had become out-of-step with changes that had happened over the fifteen years since its introduction. Not the least was the Government's ratification in 2008 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
- Revising the New Zealand Disability Strategy was considered necessary to refresh and recommit government agencies, as well as the rest of New Zealand, to taking action towards becoming a non-disabling society.
- The nature of disability issues crossing all areas of life mean that often no one government agency is responsible. Instead, responsibility may be spread across several government agencies. In some areas, there is no government agency with lead responsibility. The New Zealand Disability Strategy helps to overcome the fragmentation of government policy and services for disabled people by promoting a single, coherent and rights-based direction, based on the experiences of disabled people and families.
- The Office for Disability Issues considers that committing to implementing the New Zealand Disability Strategy across government agencies is a high priority. It is foundational to everything else that should happen in taking action to improve life outcomes for disabled people. We welcome discussion with you on what this might involve.
- The revised New Zealand Disability Strategy 2016-2026 was approved by Cabinet in October 2016, following two rounds of public consultation around the country. Its development was also guided by a reference group made up of diverse disability sector representatives, which provided advice to the Office for Disability Issues.
- 7 The New Zealand Disability Strategy 2016-2026 consists of three parts:
  - direction setting, through five principles and approaches guiding how implementation should happen and eight outcomes that describe what needs to be achieved so that disabled people can have equal opportunities in their lives
  - accountability, through reporting against indicators and measures under the eight outcomes, in addition to the Minister's annual report to Parliament and the new six monthly reporting on implementation progress to the relevant Cabinet Committee<sup>2</sup>
  - taking action, which is organised through the repurposed Disability Action Plan containing significant actions (both cross-government and single agency led) that contribute to achieving the eight outcomes.

<sup>&</sup>lt;sup>1</sup> There is also a requirement in the New Zealand Public Health and Disability Act 2000 that the Minister for Disability Issues produces a disability strategy, which is presented to Parliament.

We expect the reporting will be to a Cabinet Committee covering social policy issues. Until confirmed, for convenience we have continued to refer to the previous Cabinet Social Policy Committee in this paper.

### Working across government is important to achieve the Strategy and realise better outcomes for disabled people

- The Office for Disability Issues welcomes discussion on how, as Minister for Disability Issues, you may be able to provide early and visible communications about the New Zealand Disability Strategy and its place amongst the Government's priorities. It is important that government agencies and the wider community understand that the new Government is committed to taking action that removes barriers limiting or preventing disabled people from equal opportunities in life.
- 9 It is also valuable for government agencies to understand the views of their responsible Minister on implementing the New Zealand Disability Strategy's direction.
- 10 Change to the status quo is needed. This will only be achieved by government agencies increasing their understanding of the lived experience of disability. This can be provided by involving disabled people and others in the policy and service development process. The greatest value is added by involving disabled people and others early, including at the problem identification stage.
- Engaging with the Disabled People's Organisations Coalition<sup>3</sup> (DPO Coalition) is one way to get the perspectives of disabled people. Other disability sector organisations can also provide advice in areas of expertise, as allies to disabled people and families. There is also a lot of value to be gained from applying a co-design approach, particularly for significant initiatives. Most recently, it has been successfully used in the Transformation of the Disability Support System work by the Ministry of Health.
- Appendix 1 lists the current disability advisory groups supported by the Office for Disability Issues and the Ministry of Social Development. Other government agencies may have engagement processes with respect to specific actions or areas of work. The Ministry of Health has several of these in place, in addition to the more recent codesign and leadership mechanisms under the transformation of the disability support system work.
- Appendix 2 describes the actors and processes supporting coordination of government agencies on disability issues. This mechanism promotes horizontal connections and leveraging of combined resources to advance change where individual action may not succeed. It is supported by the Office for Disability Issues.
- This mechanism has been focused on the Disability Action Plan and maintaining relationships with the DPO Coalition as a strategic partner. The mechanism has also been useful for engaging with the Independent Monitoring Mechanism (IMM), which consists of the Human Rights Commission, the Office of the Ombudsman, and the DPO Coalition.
- 15 The current mechanism, including engagement with Ministers, is illustrated in figure 1 below.

The DPO Coalition is a collective of six DPOs, which are working together on areas in common and representing the views of their member disabled people. More information on the DPO Coalition is in Appendix 2.

<sup>4</sup> More information on the IMM is available in Appendix 2.

# Cross-government leadership, accountability, and coordination on disability issues

### Cabinet Social Policy Committee (SOC)

- Makes decisions on disability issues across social sector portfolios
- mechanism for implementing the New Zealand Provides across government coordination Disability Strategy and CRPD
- Subsumes functions of the previously separate Ministerial Committee on Disability Issues
- Decisions confirmed by Cabinet

### Minister for Disability Issues

- Government lead/advocate for disabled people
- Meets with DPO Coalition and IMM
- Reports on implementation progress to SOC on Disability Action Plan, six monthly
- framework) progress report, annually to Parliament New Zealand Disability Strategy (and outcomes
- Submits for approval to SOC:
  - outcomes framework
- updates to Disability Action Plan
- Lead government reporting on CRPD

## Chief Executives' Group on Disability issues

- Leadership across government agencies
- Meets with DPO Coalition to discuss strategic issues and relationship between DPOs and government agencies
- Meets with IMM
- governance over the New Zealand Disability Strategy Chair acts as circuit breaker for any problem with

Membership: Ministries of Social Development, Health, Transport, Education, Justice, and Businers, Innovation and Employment; ACC and Housing NZ Corporation

## New Zealand Disability Strategy implementation governance

Joint governance is a partnership involving Senior Officials and DPO Coalition Reviews evidence of implementation progress (includes input from IMM) Maintains co-design working relationship

Aderstands emerging issues

- Makes, decisions on Disability Action Plan and approves progress reports to SOC existions on individual actions is the responsibility of action lead organisation
  - Achicle for implementing the CRPD

Sentor Officials' Group

on Disability Issues

### DPO Coalition

- Provides collective insight from lived experience of disability
- Partner in decision making

New Zealand Disability Strategy and the

Manages implementation of the

CRPD across government agencies

Provides support for discussions by the Chief Executives' Group and Ministers

- Partner in IMM
- Meets with Chief Executives' Group on Disability Issues and Ministers

First, Deaf Aotearoa, Kapo Maori, Blind Citizers, and Membership: Disabled Persons Assembly, People

Transport, Education, Justice, and Business, Innovation Membership: Ministries of Social Development, Health

and Employment; ACC and Housing NZ Corporation

and Stats NZ

## Independent Monitoring Mechanism (IMM)

- Provides input of evidence and insight from monitoring activities and disabled people's experiences
  - Meets with Ministers and Chief Executives' Group on Disability Issues Membership: Human Rights Commission; Office of the Ombudaman; DRO Coalition

facilitates, advises and monitors implementation of the New Zealand Disability Strategy; and Office for Disability Issues - focal point on disability issues within government: coordinates, supports the Minister for Disability Issues. Lead coordination of CRPD reporting.

Government actor Civil society actor

October 2017 - A9983372



The previous approach to ministerial engagement ceased to function

- In September 2008, the absence of high-level ministerial leadership on disability issues across government agencies was identified as a problem by the Social Services Select Committee in its Inquiry into the Quality of Care and Provision of Services for People with Disabilities report.
- In 2009, in response, the then Government decided to establish the Ministerial Committee on Disability Issues. Chaired by the Minister for Disability Issues, it was designed to be a separate committee that set priorities for action in relation to disabled people and held government agencies to account. The IMM also had the

- opportunity to meet with the Ministerial Committee on Disability Issues at least once a year to discuss priorities and progress with implementing the CRPD.
- 27 The Ministerial Committee on Disability Issues had mixed success during its operation. It was always challenging to get the wide range of Ministers identified as members<sup>5</sup> to attend. Similarly, a broad agenda was often not seen as relevant to every Minister. Any decision required would still need to go to the relevant Cabinet Committee. However, having some explicit engagement with Ministers was useful in maintaining engagement of senior officials.

There is a significant amount of disability-related activity due in 2018 needing Ministers' engagement

- The Office for Disability Issues anticipates that 2018 will be a busy year on disability issues. In particularly, the Disability Action Plan is due to be updated, which will need to involve public consultation. Also, the next periodic reporting to the United Nations on the CRPD will start from March 2018, when the United Nations Committee on the Rights of Persons with Disabilities releases its List of Issues.
- 29 These activities involve coordination across government agencies to produce agreed New Zealand Government products. While the Office for Disability Issues will lead and coordinate the work amongst officials and public consultation, any enhancement in Ministerial engagement on disability issues will assist government agencies responsiveness and active participate in these processes.

### High priority and aligned disability-related activity in other portfolios will advance the New Zealand Disability Strategy

Transformation of the disability support system were by the Ministry of Health

- The current disability support system does not provide disabled people and their families with choice and control over their lives. Work is underway to transform the system, based on co-design with disabled people. It aligns with the New Zealand Disability Strategy outcome 7: Choice and Control We have choice and control over our lives.
- The transformation of the disability support system programme is based on the Enabling Good Lives vision and principles. The co-design process is being informed by lessons from the two demonstrations of the Enabling Good Lives approach in Christchurch and the Waikato as well as other evidence of what works.
- The transformation programme aims to ensure disabled people, their families and whanau have greater choice and control over the support they receive from government, including individualised funding. You jointly lead the programme with the Associate Minister of Health. The Ministry of Health is the lead agency, and the Ministry provides support for the system transformation work.
- The next phase is the detailed co-design of the prototype for the MidCentral District Health Board region, currently proposed for roll-out from July 2018.
- 34 The transformed disability support system will:
  - be proactive and responsive, welcoming people into the system

In 2009, the following Ministers are identified as core members of the Ministerial Committee on Disability Issues, with the Chair (the Minister for Disability Issues) having the power to invite other Ministers to meetings, as appropriate: Minister for Tertiary Education, Skills and Employment, Minister of Health, Minister of Justice, Minister for ACC, Minister of Education, Minister for Social Development, Minister of Housing, Minister for Senior Citizens, Associate Minister of Transport. The Deputy Prime Minister/Minister of Finance was also initially nominally a member. There had also been calls for all population-based Ministers to also become Ministers (for example, the Minister for Maori Development or Women).

- offer access to independent facilitation (to help people plan for the life they want)
- provide a personal budget made up of funding from multiple government agencies
- target services more effectively to help disabled people and their whānau achieve better outcomes and reduce long-term disability costs
- refer people to other agencies for additional services
- use data analytics and system insights to monitor outcomes and continually improve the system.

### The Learning Support Update – led by the Ministry of Education

- 35 The Learning Support Update seeks to strengthen the inclusiveness of the education system by undertaking detailed design of a new learning support service delivery model. The objective is to make learning support easier to access, child-centred and better integrated with other health and social services, so that children and young people with learning support needs get the right support when they need it.
- The new service delivery model is an improved way to coordinate and manage the assessment, allocation and monitoring of learning support within the context of Communities of Learning (Kahui Ako). Its key elements are:
  - a learning support facilitator in each Community of Learning who will provide an initial point of access and coordination.
  - ensuring children and young people get the additional support that they need as they move through their educational pathway
  - capturing and sharing data about learning support needs.
- There is the opportunity to create greater alignment between the New Zealand Disability Strategy and the Learning Support Update. The Learning Support Update aligns with the New Zealand Disability Strategy outcome 1: Education We get an excellent education and achieve our potential throughout our lives.
- Our New Zealand Disability Strategy Reference Group have identified the following indicators of progress for children and young people with disabilities in the education:
  - Disabled students, and their family and whānau are welcomed at the school or education setting of their choice.
  - Disabled people participate and are included in the entire education system and extra curricular activities.
  - Disabled people have positive experiences in education.
  - Disabled people achieve and progress in education.
  - Disabled students, their parents, and whānau, are well informed about their options and rights.

### Disability Confident campaign - led by the Ministry of Social Development

- 39 The Disability Confident campaign was launched in November 2016 and recognises that disabled people are an untapped talent pool of loyal and committed employees. They bring a perspective that can help transform a business' culture, customer relations and performance for the better.
- The campaign is a partnership between government and the private sector, and provides employers with the practical tools and information to have the confidence to hire disabled people.
- It is aligned with the New Zealand Disability Strategy outcome 2: Employment and economic security We have security in our economic situation and can achieve our full potential.

A lot of government funding goes towards supports and services for disabled people

- The significant amount of government funding that is spent on direct supports for disabled people may also be considered as needing greater Ministerial engagement. In particular, Ministers may want to ensure the funding is efficient and effective in providing disabled people and families with what they need to have equal opportunities in life. The transformation of the disability support system work is scoping what elements of the overall disability-related funding can be included in the transformation programme.
- In 2017, the Office for Disability Issues estimated that, based on information provided by government agencies, around \$4.5 billion was appropriated for 2017/2018 on services and supports specifically for disabled people (who are mostly under 65 years old). Appendix 3 provides details of the estimate.
- This is a conservative estimate, because some funding is not disaggregated strictly into supports for disabled people and therefore cannot be counted separately. This is particularly the case in health funding for older people and general mental health services, which are a mixture of disability support and health treatments. Another example is income support provided by the Ministry of Social Development, such as the Jobseeker Support benefit for people with health condition or disabilities.
- The estimate only included funding where disabled people were clearly the sole recipients. It is likely that a more complete accounting would result in a larger amount of funding used by disabled people

Also, any mainstream or indirect supports, or services used by disabled people is similarly not included.

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Author: 9(2)(a) Senior Advisor, Office for Disability Issues

Responsible manager: Brian Coffey, Director, Office for Disability Issues

## Appendix 1: Disability-related advisory groups

The following advisory groups support the work of the Ministry of Social Development and the Office for Disability Issues.

Note: while the Ministry of Health is leading the transformation of the disability support system work, the Ministry of Social Development continues to manage support for the earlier, related Enabling Good Lives demonstrations in the Waikato and Christchurch.

Name of group	Purpose	Membership	Appointment	Supported by
National Enabling Good Lives Leadership Group (NEGL)	NEGL provides disability community and sector input to and advice on current and future initiatives involving changes to the disability support system.	Gary Williams (co-chair) – Individual, disability sector leader Latoa Halatau (co-chair) – Vision Pactic Jade Farrar – individual, background in disabled youth development Anne Wilkinson – individual, parent/family representative Gerri Pomeroy – National Executive Committee member and President; Waikato branch Disabled Persons Assembly; Access Coordinator, CCS Disability Action Waikato John Taylor – Executive Director, Community Connections Pati Umaga – President of Disabled Persons Assembly NZ Inc. Mark Benjamin – Chief Executive, Standards and Monitoring Services	NEGL will have up to nine members in total. The NEGL fill vacancies by seeking nominations from the Disabled People's Organisations' group, the New Zealand Disability Support Network, the Family Leadership Alliance, the Christchurch Enabling Good Lives Local Advisory Group, and the Waikato Enabling Good the Seadership Group. NEGL will ensure that disabled people are in the majority.	Ministry of Social Development (Youth and Disability team, Community and Family Policy) [this may move to the Ministry of Health, to be confirmed]
Enabling Good Lives Waikato Leadership Group	<ul> <li>Ensure that disabled people, family/whānau, service providers and persons with disabilities' advocates and organisations are engaged in the Enabling Good Lives approach in Waikato.</li> <li>Be 'champions for change' and ensure momentum with the Enabling Good</li> </ul>	The terms of reference specify four disabled people, three family members and three provider spaces (shared between four representatives) on the Leadership Group, as well as Four Maori members. A member of each contributing Agency also attends, ie - MOH, MSD, MOE.  Current membership is:  Glen Terry (People First representative)  Gerri Pomeroy (DPA representative)  Helena Tuteao (DPA representative and Māori disabled person)	Some members are appointed by representative bodies, others emerged through networks	External facilitation by Mark Benjamin, a member of the National EGL Leadership Group. Logistic support from the EGL

Name of group	Purpose	Membership	Appointment	Supported by
	Lives approach in the Waikato.  Promote and protect the Enabling Good Lives principles and approaches in the Waikato.  Use a co-design approach to develop and monitor the Demonstration.	Jean Masters (representing the Deaf Community)      Anne Wilkinson (family representative)     Karinga Jothnson (family representative)      Maliah Edwardson (whānau representative)     Jahelle Fisher (Inclusive NZ representative)      Samantha (ee(NZDSN representative)      Samantha (ee(NZDSN representative)      Kathryn Numa (NZDSN representative)      Kathryn Numa (NZDSN representative)  disabled and Māori provider.		and team.
New Zealand Sign Language Board (NZSL Board)	The purpose of the NZSL Board is to:  • promote and maintain the use of NZSL by ensuring the development and preservation and acquisition of the language • ensure the rights of Deaf people and NZSL users to use NZSL as outlined in the NZSL Act 2006 and United Nations Convention on the	Victoria Manning – (Chair of the Board) tridividual; has been an active member of the Deaf community in various leadership roles in the Deaf community and promoting NZSL for over 26 means.  Sara Pivac Alexander – individual; is a New Zealand Sign Language lecturer and a member of the Deaf Studies Research Unit at Victoria University of Wellington.  Richard Peri - individual; is a teacher of New Zealand Sign Language and Te Reo sign, who has strong skills in leadership and communitation. He has affiliations with Ngati Porou and Te Rarawa.  Bridget Ferguson – representative of Deaf Aotearoa; has been involved in the Deaf community and using New Zealand Sign Language for over 24 years as a professional sign language interpreter, a resource teacher of the Deaf, advisor on Deaf children and as a mother of Deaf children.  Josje Lelijveld - individual; is the Vice President of the Deaf Society of Canterbury and is involved with several other advisory groups. Josje	The Minister for Disability Issues recommends appointments to the Cabinet Appointments and Honours Committee, after considering advice from a selection panel convened by the Office for Disability Issues.  The NZSL Board has up to 10 members in total, all of whom are NZSL users, and a majority of members will be Deaf NZSL users.	Office for Disability Issues

Name of group	Purpose	Membership	Appointment	Supported by
	Rights of Persons with Disabilities and other national and relevant international legislation  provide expert advice to government and the community on NZSL, including recommendations on allocation of the NZSL Fund.	currently teaches New Zealand Sign Language at the University of Canterbury to students of Specialist Teaching (Deaf and Hearing Impaired).  Dr Rachel McKee, individual; has 30 years of involvement in the New Zealand Sign Language Community, in the roles of interpreter, Deaf Studies researcher and lecturer, and social participant in the community. Shona Jones, individual; has worked at the Kelston Deaf Education Centre (KDEC) for 14 years, initially as a teacher and more recently as the Pre-school Manager for the Centre. Shona has been involved in the deaf community all her life.  Chris Blum - individual, has had extensive involvement in the deaf community, including teaching M2st at Natekland University of Technology, involvement in Deaf Mehental Health Services, and the Friend for the Young Deaf leadership training.  Lee Bullivant - individual; has wide experience in the deaf community, and brings to the NZSL Board an understanding of the issues facing New Zealand Sign Language users who are in regional towns of isolated communities.  Dr Kirsten Smiler - Dr Smiler is a Senior Mãori Research Feliow at the Health Services Research Centre, Victoria University of Wellington, She has worked on numerous research projects around (the area of Mãori health and disability.		
Disability Data	Define, clarify and prioritise	The Working Group has representatives from:	Director, Office for Disability	Office for
and Evidence Working Group	information needs to improve the lives of disabled people,	Stats NZ	sanssi	Disability Issues
	and inform better quality monitoring of and reporting on	Office for Disability Issues     Mainter of Social Development		
	the Convention of the Rights of Persons with Disabilities, the	Ministry of Health		
	New Zealand Disability Strategy	Ministry of Education		

and the Disability Action Plan  Support decision-making on resource allocation resource allocation Reference Group Disability  Reference Group Disability  Reference Group Disability Reference Group in list 2013 to support the development of the Health and Disability Long Term Work Programme (LTWP), which included a range of initiatives to increase the employment of disabled people and people with health conditions. The LTWP has since finished as all the actions have either been completed consolidated			
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## Appendix 2: Cross-government leadership, accountability and coordination on disability issues mechanism

The current mechanism promoting cross-government leadership, accountability and coordination on disability issues comprises the following committees and meeting processes.

including monitoring of progress with implementing the New Zealand Disability Strategy and reporting. The Office for Disability Issues The Office for Disability Issues provides secretariation to provide secretariation and the DPO Coalition,

also provides independent advice as an actor in its own right in the mechanism.

The mechanism provides opportunities to engage with other parties, including the Independent Monitoring Mechanism (comprising the Human Rights Commission, Office of the Ombudsman and DPO Coalition).

Name of group/process	Role	Functions	Membership	Appointment	Supported by
Chief Executives' Group on Disability Issues	Leadership on strategic disability issues and the relationship between government agencies and the DPO Coalition will be strengthened and sustained by meetings between the Chief Executives' Group on Disability Issues and the DPO Coalition.	<ul> <li>Demonstrates the Government's commitment to improving the lives of disabled people, through providing Eross government leadership for implementation of the New Zeafand Disability Strategy and the CRPD.</li> <li>Provides a forum for considering strategicand emerging issues impacting on disabled people and ensures good working relationships between government agencies and the disability community (particularly with the DPO Coalition).</li> <li>Enables the lived experience of disabled people to inform and influence government thinking and design of legislation policy, and practice.</li> <li>Enables the disability community (particularly with the DPO Coalition) to gain a better understanding of how government agencies work and opportunities for influencing priority setting.</li> <li>Two meetings will be held each year.</li> </ul>	Chief Executives of participating government agencies will form the Chief Executives' Group on Disability Issues.  Current participating government agencies are:  Social Development Health Education ACC  Business, Innovation and Employment and Employment Transport  Transport  Corporation.	Self- determining, and advice from the Office for Disability Issues.	Office for Disability Issues
			Note: the DPO Coalition		

Name of group/process	Role	Functions	Membership	Appointment	Supported by
And the second of the second o			has recently requested that Te Puni Kokiri and the Ministry of Pacific People be invited to join.		
Senior Officials Group on Disability Issues	Manages, coordinates and supports government agencies' implementation and reporting on the New Zealand Disability Strategy, including engagement with the DPO Coalition.	Manages, cross, government implementation of the New Zealand Disability Strategy, and the CRPD, and any other disability-related matters.  Meets with the CRPD calition to provide joint governance over implementation of the New Zealand Disability Strategy.  Facilitates engagement between the CPD Coalition and government agencies, particularly but not implementation of the New Zealand Disability, Strategy.  Facilitates the development and implementation of the Disability Action Plan, including monitoring progress and Considering any need for intervention to support implementation.  Facilitates six monthly reporting to the Cabinet Social Policy Committee by the Minister for Disability (Souss, which is prepared by the Office for Disability Issues.  Facilitates treaty reporting regarding disabled Wew Zealanders particularly for the periodic reviews of the CRPD implementation disabled people and sharing disability-related news and disabled people and sharing disability-related news and prepared for any engagement with the DPO Coalition, IMM or other disability-related matters.	Senior Officials of government agencies, who have decision making authority from their agency and can actively contribute and participate, will form the Senior Officials' Group on Disability Issues.  Senior Officials may typically be General Managers/Group Managers/Group Managers (tier 3) or Deputy Chief Executives (tier 2) as appropriate for each government agency.  Current participating Social Development  Health  Education  ACC  Justice  Business, Innovation and Employment  Transport  Transport  Housing NZ	Self- determining, and advice from the Office for Disability Issues.	Office for Disability Issues

Name of group/process	Role	Functions	Membership	Appointment	Supported by
			Corporation • StatNZ.		
Joint governance of the New Zealand Disability Strategy implementation	Governance over implementation of the New Zealand Disability Strategy will be jointly provided through meetings between the Senior Officials' Group on Disability Issues and the DPO Coalition.	Governance over implementation of the New Zealand Disability Strategy, principally through its Disability Action Plan, is provided by joint meetings of the OPO Coalition and Senior Officials' Group on Disability Strategy of involving disabled people in decision making about them.  The joint meetings:  The joint meetings about them.  The joint meetings about them.  The joint meetings of actions in the New Zealand Disability Action Plan of Inger be needed because they are overfaken by events on actions at risk  The possibility Action Plan (which are subsequently published on the Office for Disability Issues' website)  There may be times and learning on disability Action Plan to the Cabinet Social Policy Committee every six months  Share experiences and learning on disability-related initiatives  build and enhance relationships between government agencies and the DPO Coalition.  There may be times where consensus is not possible due to fundamental differences in position. Government agencies and the DPO Coalition may reserve the right to state different positions, such as in reporting to the Cabinet Social Policy	Senior Officials' Group on Disability Issues DPO Coalition representatives	Not applicable	Office for Disability Issues

Name of group/process	Role	Functions	Membership	Appointment	Supported by
		Committee.			
Independent Monitoring Mechanism (IMM)	Provides an independent view of New Zealand's implementation of the United Nations Convention on the Rights of Persons with Disabilities (and the New Zealand Disability Strategy). The IMM meets a requirement in Article 33 of the Convention.	The three partners in the IMM (the Human Rights Commission, the Office of the Ombudsman, and the DPO Coalition) gather evidence on disabled people's expecification of their rights through:  - separate activities, within each partner's mandates by applying a disability-lens  - specific commissioned activities by a partner on a disability-related topic (for example, the human Rights Commission has published a report on the practice of seclusion and restraint)  - jointly commissioned activities for example, the IMM has produced two reports since 2013  - engagement with the United Nations Committee on the Rights of Persons with Disabilities (which oversees the CRPD), particularly during the periodic reporting process.	The IMM consists of three equal partners:  - Human Rights Commission - Office of the Ombudsman - DPO Coalition	In 2010, Cabinet designated the membership, role and functions of the IMM.	Self supporting The Office for Disability Issues manages funding for the DPO Coalition to carry out monitoring of individual experiences of disabled people's rights.
Disabled People's Organisations (DPO) Coalition	Provides a nationally focused, collective forum of Disabled People's Organisations representing disabled people's views and experiences.	y through regular meetings in governance-level representatives of governance-level representatives of their with government agencies in nince, and provide advice to individual v-related initiatives.  Ition participate alongside other advisory groups operated by e the New Zealand Disability p and the National Enabling Good this led by disabled people,	The DPO Coalition currently consists of: Blind Citizens People First Deaf Aotearoa - Balance Aotearoa - Kapo Maori - Disabled Persons Assembly.	The DPO Coalition considers applications for membership from organisations, which need to demonstrate the attributes of being a Disabled People's	The Office for Disability Issues works closely with the DPO Coalition, and provides funding for its meetings.

Name of group/process	Role	Functions	Membership	Appointment	Supported by
		advocates on behalf of disabled people, and has a membership of disabled people. The CRPD recognises there is a need for DPOs to be involved and actively consulted on government decisions impacting on disabled people. However, this is in addition to and not excluding any other disability sector representation.		Organisation.	

was sector begins and not excluding

### Appendix 3: Estimated direct funding for disability supports

The following provides information on the amount government spends on disability services and the number of people who use these services. It is based on information available in July 2017.

The last estimate in 2015 was around \$4.2 billion. It was prepared by an individual who was commissioned by the Office for Disability Issues (ODI). The report was on "direct expenditure including services and supports that only disabled people are eligible for, such as the services from the Disability Support Services (DSS) of the Ministry of Health (MOH) or the Disability Allowance from the Ministry of Social Development (MSD)."

This capture excluded any indirect or merged categories of spending which may include disabled people but which it is not easily or at all possible to disaggregate on disabled people alone. For example, disabled people on Jobseeker Support Benefit.

For the 2017 estimate, ODI took the approach of asking agencies the question of how much they spend on disability services each year. Please note that this has resulted in a different figure than provided in the 2015 estimate.

For the financial year of 2016/17 we estimate that direct government expenditure on disability services was \$4.5 billion. With rounding to \$100,000s there is little change indicated over the 2015/16 to 2017/18.

The table and graph below represent estimated government spend per financial year, since 2008/09.

Year S	Government spend (billions)
2008/09	3.7
2015/16	4.5
2016/17	4.5
2017/18 (forecast)	4.5

ACC is funded in part by government (for injury claims by non-earners, except for injuries from motor vehicle accidents) and in part by levies (work, earners and motor vehicle). NZTA is funded in part by government and in part through the National Land Transport Fund. The total direct government expenditure on disability services includes spending from ACC and the National Land Transport Fund (consistent with the August 2015 report).

Key disability-related mechanisms, support and processes

Vote	Agency	Type of expenditure	Appropriation			The Estimates of App	The Estimates of Appropriations 2016/17/18
				2008/09 (\$ million)	2015/16 (\$ million)	2016/17 Final Budgeted (\$ million)	2017/18 Budget (\$ million)
Social Development	Ministry of Social Development	Non-Departmental Benefits	Disability Assistance (including Disability Allowance, Child Disability Allowance)	391.06	378.9	380.02	379.49
Social Development	Ministry of Social Development	Non-Departmental Benefits	Supported Living Payment	•	1,519.5	1,537.22	1,530.88
Social Development	Ministry of Social Development	Benefits and Other Unrequited Expenses	Invalids Benefit	1,261.61	ı	1	•
Social Development	Ministry of Social Development	Departmental outputs and expenditures	Promoting Positive Outcomes for Disabled People (including NZSL Fund, OD), monitoring by disabled people)	\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\	5.8	4.04	3.71
Social Development	Ministry of Social Development	Departmental outputs and expenditures	Community Participation Services		77.5	82.63	81.16
Social Development	Ministry of Social Development	Departmental outputs and expenditures	Assistance to Disadvantaged Persons	1.45	0.9	1	1
Social Development	Ministry of Social Development	Departmental outputs and expenditures	Participation and Inclusion for Disabled People (formally vocational services for people with disabilities)	88.24	74.8	•	
Social Development	Ministry of Social Development		Totals COLD	1742.36	2057.4	2003.91	1995.24
Health	Ministry of Health	Non-Departmental Output Expenses	National Disability, Support Services	888.6	1,167.7	1,188.3	1,208.4
			Community Care	180.7	285.7	289.1	Not available
			Residential Care	380.0	515.6	527.8	Not available
			Enylronmental Support	109.7	132.0	141.7	Not available
			Rehabilitation	35.6	44.5	43.6	Not available
			Child Development	21.9	23.5	23.5	Not available
			High and Complex Needs	67.1	74.2	74.7	Not available
			Needs Assessment and Service Coordination	27.8	21.9	22.3	Not available
			Funded Family Care	1	5.9	9.0	Not available
			Other	62.9	64.5	56.8	Not available
Health	Ministry of Health	Operating expenditure	Total	888.6	1,167.7	1,188.3	1,208.4
Education	Ministry of Education	Departmental	Interventions for Target Students Groups (Ministry specialist services)		109.89	116.18	
Education	Ministry of Education	Non-departmental	Special Education Grant to schools operating funding		38.91	39.19	
Education	Ministry of Education	Non-departmental	Specialist teachers – Resource Teachers Learning and Behaviour, Resource		84.86	86.94	

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Vote	Agency	Type of expenditure	Appropriation	BALL SERVERSEE		The Estimates of Appr	The Estimates of Appropriations 2016/17/18
				2008/09 (\$ million)	2015/16 (\$ million)	2016/17 Final Budgeted (\$ million)	2017/18 Budget (\$ million)
Education	Ministry of Education	Non-departmental	Special Needs School Transport		39.44	40.10	
Education	Ministry of Education	Non-departmental	Special Schools		75.26	92.43	
Education	Ministry of Education	Departmental	Assistive Technology		3.34	3.64	
Education	Ministry of Education	Departmental	Teacher aide and support worker support for non ORS		34.09	41.39	
Education	Ministry of Education	Non-departmental and departmental	ORS teacher aide, specialist teacher, and school based specialist services (excl Ministry provided ORS services)		168.70	172.20	
Education	Ministry of Education	Non-departmental	NZSL teaching		2.84	3.22	
Education	Ministry of Education	Non-departmental	School based PB4L initiatives (positive behaviour for learning)	T.	16.06	15.94	
Education	Ministry of Education	Non-departmental and departmental	Miscellaneous	5	17.98	21.47	
Education	Ministry of Education	を 一	Total (O)	1 1 439	591.37	632.57	632.57
Business, Science and Innovation	Ministry of Business, Innovation and Employment	Non-departmental	Telecommunications – Relay Services	0.25	1.29	1.51	1
Business, Science and Innovation	Ministry of Business, Innovation and Employment	Non-departmental	TLD Funded Procurement – Deaf Relay Service 150	,	2.66	3.0	1
Business, Science and Innovation	Ministry of Business, Innovation and Employment	Non-departmental	Acquisition of Textphone Equipment	0.09	-	0.16	
Business, Science and Innovation	Ministry of Business, Innovation and Employment	Non-departmental	Services for Deaf, Hearing Impaired and Speech Impaired People	1	1	1	4.68
Business, Science and Innovation	Ministry of Business, Innovation and Employment		Total	0.34	3.95	4.67	4.68
Defence Force	Veteran's Affairs		War Disablement Pension/Veteran Support Entitlement (including Surviving Spouse Pension)	124.95	106.69	99.44	90.91
Defence Force	Veteran's Affairs		Medical Treatment/Assessments, Treatment and Rehabilitation	19.18	7.80	13.05	11.59
Defence Force	Veteran's Affairs		Ex Gratia Payments and Comprehensive Medical Assessments for Vietnam Veterans	0.59	0.08	0.92	1.1
Defence Force	Veteran's Affairs		Veterans Independence Programme (commenced 07/12/15)	•	3.90	9.19	11.24
Defence Force	Veteran's Affairs		Total	144.72	118.47	122.60	114.84
Labour Market	ACC (for serious injury clients only)		Support for Independence - Capital	52.67	65.27		
Labour Market	ACC (for serious injury clients only)		Support for independence – Non Capital	250.45	323.46		
			Other Entitlement Costs	112.29	143.25		

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			2008/09 (\$ million)	2015/16 (\$ million)	2016/17 Final Budgeted (\$ million)	2017/18 Budget (\$ million)
	ACC (serious injury clients that are also treatment injury clients)	Social Rehab Costs	28.14	45.01		
	ACC (serious injury clients that are also treatment injury clients)	Other Entitlement Costs	4.02	7.79		
Labour Market		Total	447.59	584.80	584.80	584.80
	New Zealand Transport Agency	Total Mobility scheme: National Land Transport Programme share	7.71	11.87	12.82	12.73
	New Zealand Transport Agency	Total Mobility scheme: Local Government share	5.14	6.37	4.44	4.48
	New Zealand Transport Agency	Total (A)	12.85	18.24	17.26	17.21

### **Caveats and Explanations**

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### Education

Learning Support expenditure covers a number of appropriations including interventions for target students, national study awards, special needs support, special needs transport and other outputs.

The figures included are those that are most likely to benefit children with disability support needs and exclude departmental overheads. Some figures are estimates such as specialist teacher costs as actual teacher salaries will vary, and it is not possible to extract from the payroll system actual salaries for specialist teachers. So the figures are estimated as number of positions times an estimated average salary rate.

The estimate for 2017/2018 is assuming that the learning support (not yet costed) will be at least the same as the previous year.

Business, Science and Innovation

The three former telecommunications relax appropriations have been merged into a new Multi-Category Appropriation for 2017/18 Services for Deaf, Hearing Impaired and Speech Impaired People).

Veterans' Affairs

Caveat from Veteran's Affairs: We note that disability is specifically defined for MOH purposes under legislation, and that definition is not the definition used by Veterans' Affairs. This means that conditions that Veterans' Affairs terms disabilities and funds are not conditions defined by MOH as a disability and vice versa. We are therefore not comparing apples with apples

Veterans' Affairs funds treatment, rehabilitation and support for veterans (including those residing overseas) with service-related injuries and illnesses. Veterans' Affairs may also provide (im)ted support to eligible veterans with non-service related injuries and illness under the Veterans' Independence Programme to assist them to live independently at home. Injuries and illnesses that may be covered under the Veterans' Support Act 2014 may not fall within the Ministry of Health's definition of disability. Veterans' Affairs is not responsible for paying or contributing to the costs of treatment, rehabilitation and support services if these are available under the New Zealand Public Health and Disability Act 2000 or from ACC.

### ACC

The estimate for 2016/2017 and 2017/2018 is assuming that funding will be at least the same as it was in the previous year (given the upward trend).

### Caveats

- The figures reflect when the service or good was paid for, which in some cases may differ from when the service was provided.
- Costs are exclusive of GST.

- The data was extracted on 30 June 2017, and the figures may change if re-run at a later date.
- Support for Independence Capital includes payments for equipment, housing modifications and vehicles, etc.
- Support for Independence Non Capital includes payments for care, assessments and training, etc.
- Other Entitlements include treatment payments (e.g. surgery) as well as financial support (weekly compensation, lump sum and independence allowance).
- ACC claims are funded by levies (Work, Earners and Motor Vehicle) or from the Government, depending on the circumstances. Government funding is for injury claims by non-earners, except for injuries from motor vehicle accidents. Given this, the costs provided in Table 1 are not representative of Government spend.
- We cannot provide figures for 2016/17 and 2017/18.

How many disabled people are there in New Zealand approximately how many access government support for their disability?

Statistics New Zealand's 2013 Disability Survey estimated that there are 1.1 million New Zealanders who are disabled.

For the Disability Survey, disability was defined as long-term limitation (resulting from impairment) in a person's ability to carry out daily activities. The limitations identified were self-reported or reported on behalf of the disabled person by their parent or primary caregiver. The survey collected data from adults (aged 15 years or over) and children (under 15 years) living in private households or group homes and from adults living in residential care facilities. All of these groups are included in the data, except where stated.

The following table shows how many people access services/supports. It is important to note that there will be some people who are counted multiple times across the different categories. For example, a person using the Total Mobility Scheme may also receive the Support Living Payment. Therefore, totalling the 'number of people accessing the support' will not provide the total number of individuals receiving support.

Agency	Service/Support	Number of people accessing the service/support
MSD	Disability Assistance (including Disability Allowance, Child Disability Allowance)	In June 2016, there were 35,105 recipients of the Child Disability Allowance.  In March 2017, 235,158 Disability Allowances were paid.
	Supported Living Payment	In June 2016, there were 97,600 recipients of the Supported Living Payment.
	Promoting Positive Outcomes for Disabled People (including NZSL Fund, ODI, monitoring by disabled people)	This support is not provided to individual people.
	Community Participation Services	The number of disabled people supported to participate in their communities was 16,500 for the year ending June 2017.

мон	National Disability Support Services	As at September 2014, there were 32,247 clients of disability support services.
MOE	Learning Support	30,000 children and young people receive specialist support through Ministry of Education administered services.     Approximately 8,300 students with very high needs receive high intensity support from schools through the Ongoing Resourcing Scheme (ORS).     Schools also support approximately 30,000 to 50,000 children and young people students with mild to moderate needs.  Total number of children and young people supported = 68,300 to 88,300.
MBIE	Communications: Services for	We cannot quantify how many people use the services. The relay
	Deaf, Hearing Impaired and	service has no obligation for users to register and effectively prove
	Speech Impaired People	that they have a disability. The service caters to deaf, hearing
		impaired, deafblind and speech impaired people in New Zealand.
Veteran's	War Disablement	7,515
Affairs	Pension/Disablement Pension	
	Independent Allowance/Lump Sum	8
	Income Replacement	34
	Veterans Independence Programme	3452
	Ex-gratia Payments and Comprehensive Medical Assessments for Vietnam Veterans	567
		at compensation are eligible for the cost of treatment and rehabilitation
ACC	Support for Independence - Capital	3,701
	Support for Independence – Non Capital	4,667
	Other Entitlements	5,006
A claim car	n be counted in multiple payment grou	ıps.
NZTA	Total Mobility Scheme	In 2015/16, there were 78,131 registered users of the Total Mobility Scheme.



### Report

Date:

20 December 2017

Security Level: IN CONFIDENCE

To:

Hon Carmel Sepuloni, Minister for Disability Issues

### **Disability Data**

### **Purpose of this Briefing**

1 The purpose of this briefing is to inform you about:

- why we need more data on disabled people in New Zealand
- the data that is currently available and recent progress made
- gaps in the data.
- There has been recent progress on improving the availability of disability data in New Zealand. However, there remains important work to be undertaken in early 2018 to address the data needed to measure progress specific to indicators being developed as part of the New Zealand Disability Strategy (2016-2026) Outcomes Framework.
- The result of this work will also contribute to implementing the United Nations
  Committee on the Rights of Persons with Disabilities recommendation for States
  Parties to develop better disability data to inform realisation of the rights of disabled people.
- 4 The Office for Disability Issues (ODI) has been working closely with Stats NZ on disability data issues and in preparing this report.

### **Recommended actions**

- 5 At the next agency meeting, it is recommended that you note for discussion the need to collect more data on disabled people.
- 6 Our immediate recommendation is that you:
  - note that we need more frequent collection of data on disabled people

9(2)(f)(iv)

Brian Coffey

Date

Director, Office for Disability Issues

### The collection of reliable and valid data on disabled people is important

- 1 The availability of robust data on disabled people is vital:
  - to inform policy development, service planning and practice
  - to track progress in the implementation of the New Zealand Disability Strategy 2016-2026 (the Disability Strategy)
  - to monitor and evaluate effectively New Zealand's progress in implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The requirement to measure and report on progress for disabled people against the outcomes of the Disability Strategy and the UNCRPD highlight the need for collecting high quality disability data

The Disability Strategy Outcomes Framework is being developed to provide data on progress

- An Outcomes Framework is currently being developed to provide accountability for the implementation of the Disability Strategy. When consulted on the Disability Strategy disabled people voiced strongly the need to measure progress against the Disability Strategy outcomes from the perspective of disabled people.
- The Disability Strategy has a 10 year time frame with eight broad outcome domains described from the perspective of disabled people. Those outcomes are:
  - Outcome 1 Education "We get an excellent education and achieve our potential throughout our lives".
  - Outcome 2 Employment and Economic Security "We have security in our economic situation and can achieve our full potential".
  - Outcome 3 Health and wellbeing "We have the highest attainable standards of health and wellbeing".
  - Outcome 4 Rights protection and Justice "Our rights are protected, we feel safe, understood and are treated fairly and equitable by the justice system".
  - Outcome 5 Accessibility "We access all paces, services and information with dignity and ease".
  - Outcome 6 Attitudes "We are treated with dignity and respect".
  - Outcome 7 Choice and control "We have choice and control over our lives".
  - Outcome 8 Leadership. "We have great opportunities to demonstrate our leadership".
- Of paramount importance is the development of a set of valid and reliable indicators that are specific, observable and measurable, and can be tracked over time to demonstrate what change or progress is occurring against the Disability Strategy's eight outcome domains for disabled people. Robust data will be required to measure the indicators selected for each of the outcome domains. The ODI has worked with the Disability Strategy Reference Group to identify a set of indicators. The reference group was asked to identify what would indicate progress, from a disabled person's perspective, against the <sup>18(d)</sup>

5 <sup>18(d)</sup>

Initial analysis of these indicators and the data needed to measure them by the ODI shows that there are six indicators for which there is data currently available, five where data will be available, and 16 indicators where there is currently no data available to measure progress.

Concluding Observations (2014) of the United Nations Committee on the Rights of Persons with Disabilities recommended New Zealand improve disability data collection

- 7 In October 2014, the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) released its Concluding Observations on its review of New Zealand's implementation of the CRPD.
- One of the UN Committee's recommendations focused on the need for New Zealand to improve its collection of disability data.
- In response to the UN Committee's recommendation, the former Minister for Disability Issues announced the establishment of the Disability Data and Evidence Working Group (DDEWG), co-facilitated by Stats New Zealand and the Office for Disability Issues, in June 2015. The purpose of the DDEWG is to work with government agencies, the disability sector and other organisations to:
  - define, clarify and prioritise information needs in order to improve the lives of disabled people, and inform better quality monitoring of and reporting on the CRPD, the Disability Strategy and the Disability Action Plan 2014-2018<sup>1</sup>
  - support decision-making on resource allocation.

Gaps in disability data is still considered a key issue by New Zealand's Independent Monitoring Mechanism and has been raised in the second periodic review process

- In November 2017, the Independent Monitoring Mechanism (IMM)<sup>2</sup> submitted a report to the UN Committee outlining what it considers are the key issues impacting on the implementation of the CRPD in New Zealand. Large gaps in disaggregated disability data in New Zealand is considered among the most pressing issues in the IMM report to the UN Committee.
- 11 At the December 13 2012 meeting of the Minister's Leadership Group on Disability Issues the IMM recommended that Government Agencies be required to use a consistent methodology to collect disability data so that agencies could understand better their client groups and the impact of services provided for disabled people. This would also promote data integration.

### New sources of disability data are now available in New Zealand

A consistent approach to collecting data on disabled people is important

- Both Stats NZ and the DDEWG support the use of the Washington Group Short Set of questions on Disability (WGSS) and have been promoting the use of this question set. This is a short set of questions designed to be used in non-disability-specific surveys and census to identify disabled people.
- 13 The Washington Group is a UN city group established under the United Nations Statistical Commission. The WGSS was constituted to address the urgent need for cross-nationally comparable population-based measures of disability

<sup>&</sup>lt;sup>1</sup> The New Zealand Disability Strategy 2016-2026 was launched in November 2016. The Disability Action Plan 2014-2018 will be updated in 2018.

<sup>&</sup>lt;sup>2</sup> The Independent Monitoring Mechanism is made up of the Human Rights Commission, the Office of the Ombudsman and the Disabled People's Organisations Coalition.

- 14 Importantly, the WGSS questions will be included in the 2018 Population Census, which will make it possible to produce more detailed information on people with disabilities in NZ than has previously been available.
- 15 In addition, Stats NZ has already implemented the WGSS in two key household surveys:
  - The WGSS was included in the New Zealand General Social Survey (NZGSS) from 2016. The NZGSS is a biennial survey that provides information about the wellbeing of New Zealanders aged 15 years and over. It covers a wide range of social and economic outcomes and shows how people are faring in these aspects of their lives.
  - The WGSS was also included in the June 2017 quarter of the Household Labour Force Survey (HLFS), and will continue to be included in each June quarter going forward. The purpose of the HLFS is to produce a timely, relevant, and comprehensive range of statistics relating to the employed, unemployed, and those not in the labour force, using international standards and guidelines.
- In addition to the work of Stats NZ, the Ministry of Justice has recently included the WGSS in the 2017 pilot of the Crime and Victims Survey, and is likely to keep these questions in the survey to be run annually from 2018. The WGSS is also being included in the 2018/2019 New Zealand Health Survey, 9(2)(f)(iv)

Qualitative data that is not numerical in nature is also important to understand disabled people's lives

- In addition to the quantitative data collected in surveys and administrative records, qualitative data (which is useful to find out in depth how disabled people think and feel) is collected by disabled-people-led monitoring. Disabled-people-led monitoring is led by the Disabled People's Organisations Coalition (DPO Coalition).
- The qualitative data collected by disabled people themselves, who have been trained to interview their disabled peers, provides a valuable record of disabled New Zealanders' lived experience of disability. Issues covered in the published DPO coalition reports include: disabled youth, the role of the media, poverty, social participation and social attitudes.
- The qualitative data included in the DPO Coalition monitoring<sup>3</sup> reports is also used to monitor the progressive realisation of disabled people's rights outlined in the UNCRPD, and as input into reports to the United Nations.

There have been improvements in administrative data on disability

- Administrative data is collected by government agencies and specified crown entities (for example, District Health Boards) for the purpose of registration and record keeping, usually during the delivery of a service. Government agencies collecting administrative data relating to disabled people include: the Ministries of Health, Education, Social Development, Transport and the Accident Compensation Corporation.
- 21 The Integrated Data Infrastructure (IDI), managed by Stats NZ is a centralised collection of administrative and survey data. The IDI is comprised of a series of datasets from different government agencies that have been integrated. Individuals from single data sources are linked and then de-identified. The final dataset contains valuable information about different aspects of the lives of diverse groups of people and their experiences over time. Government officials can use integrated data to

<sup>&</sup>lt;sup>3</sup> The ODI is currently working with DPOs to improve the effectiveness of their monitoring.

- underpin policy development and service planning that will improve social and economic outcomes for diverse groups of New Zealanders.
- 22 It is part of Stat NZ's business plan to include the 2013 Disability Survey, the NZGSS and Census 2018 in the IDI.
- 23 Given the diversity of impairment groups with different needs within the disabled population, the inclusion of more disability datasets in the IDI will be important going forward to build up a more holistic understanding of disabled New Zealanders' lives.
- 24 Currently agencies' differing definitions of disability are a limitation on the effectiveness of the data that is available across agencies.

### There are gaps in the collection of disability data

### The New Zealand Disability Survey provides the most comprehensive data on disabled people

- A decision was made by Cabinet in 2012, given the Government's priorities at the time, to fund one post-censal survey after each population census with Te Kupenga (the Māori Social Survey) to be run in 2018. This means that a disability specific survey is scheduled to run as a post censal survey in 2023 and intended to be every 10 years thereafter.
- The main purpose of a national dedicated disability survey is to estimate the official disability prevalence rate.

  9(2)(f)(iv)
- 27 A national disability-specific survey also makes it possible to collect data on:
  - a wider range of impairment groups
  - children
  - outcomes and barriers to participation across a wider range of social and economic areas
  - use of assistive equipment
  - services.
- 28 The 2013 NZ Disability Survey included:
  - 23 questions for nine domains (vision, hearing, agility, mobility, intellectual, psychiatric/psychological, learning, speaking and remembering) to identify disabled adults (15 years or more)
  - 14 questions for nine domains (vision, hearing, agility, mobility, intellectual, psychiatric/psychological, learning, speaking and developmental delay) to identify disabled children.
- 29 A large scale disability-specific survey also allows for more disaggregation of data. The 2013 Disability Survey shows that disability rates vary by ethnic group.

### Even though valuable data is collected on disabled people in New Zealand, there are gaps in the data available

More data is required to report against the outcomes in the New Zealand Disability Strategy

- 30 Despite the increased data available on disabled people being used by government agencies, there are still data gaps in the draft set of indicators for the Outcomes Framework (Appendix One).
- 31 It will be important for any new investments in data collected on disabled New Zealanders to consider the data needs of the Outcomes Framework.



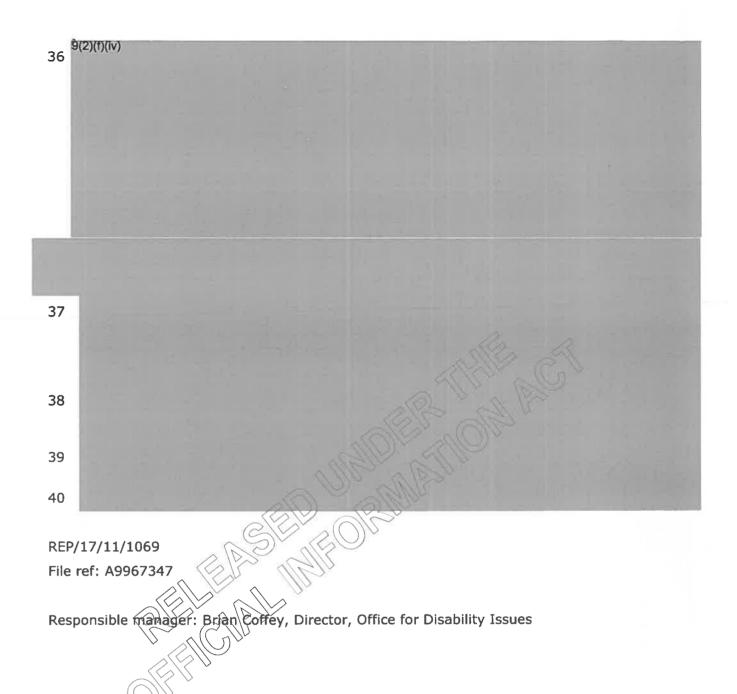
- education
- employment and economic security
- health and wellbeing
- rights protection and justice
- accessibility
- attitudes
- choice and control
- leadership.

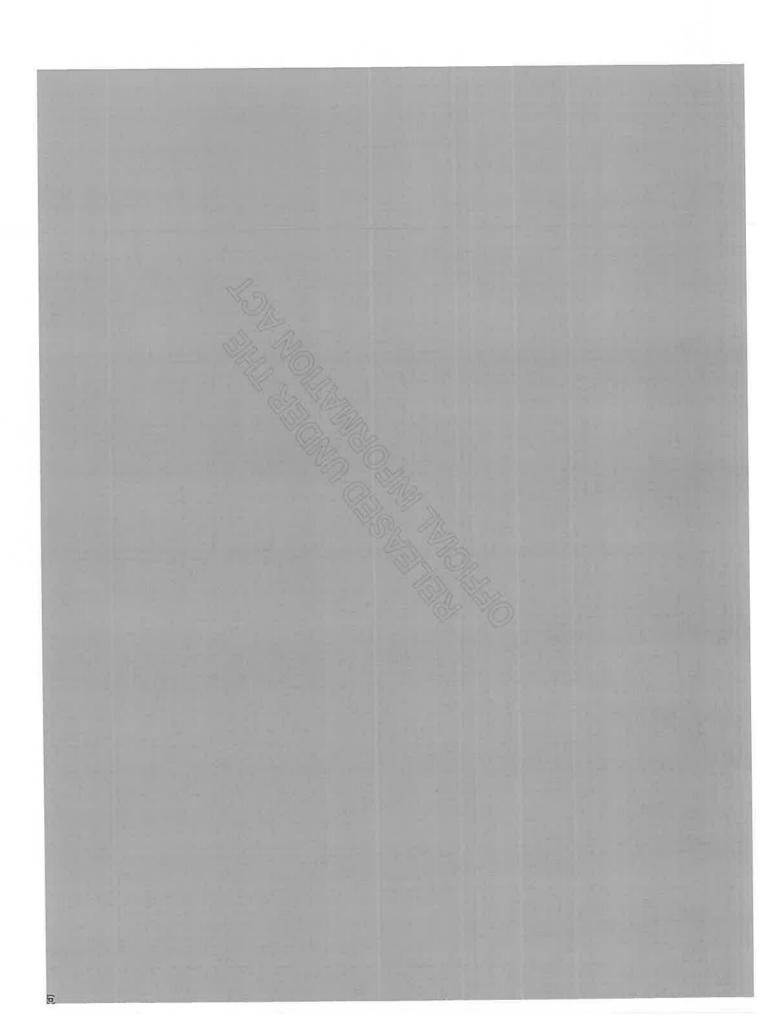
33 <sup>9(2)(g)(i)</sup>

### We need more frequent collection of data on disabled people

The NZ Disability Survey is an option, but has limitations

- 34 The NZ Disability Survey:
  - is the official source of statistics on disability prevalence rates across key demographic groups in New Zealand
  - provides information on socio-demographic characteristics of disabled people
  - collects data on met and unmet need for support and assistive equipment
  - collects data on outcomes for disabled and non-disabled people across a range of social and economic domains
  - collects data on barriers to full participation in society faced by disabled people.
- The ODI suspects that even with an increase in consistency of collection across government, there will still be data gaps in the measures required for the Strategy's eight outcome domains. 9(2)(f)(iv)







### Report

Date:

13 November 2017

Security Level: IN CONFIDENCE

To:

Hon Carmel Sepuloni, Minister for Disability Issues

### Report on the New Zealand Disability Strategy 2016 - 2026

### **Purpose of the report**

- 1. The purpose of this briefing is to inform you of the work that the Office for Disability issues (ODI) has been doing to implement the New Zealand Disability Strategy 2016-2026 (the Strategy), and about the development of an Outcomes Francework in response to Disabled People's request for there to be stronger accountability for achieving the Strategy.
- 2. We would welcome the opportunity to discuss with you the work to date on the Strategy and how the Strategy could be progressed further. A copy of the Strategy is enclosed for your reference.

Brian Coffey

Director, Office for Disability Issues

Data

### The New Zealand Disability Strategy is a key mechanism to work towards a non-disabling society

The Strategy is New Zealand's commitment to action and progressive realisation of the United Nations Convention on the Rights of Persons with Disabilities

- 3. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets out what is required to implement existing human rights as they relate to disabled people.
- 4. New Zealand was a leader in negotiating the CRPD. We modelled the spirit of participation with disabled people, by having disabled people in the government delegations in the United Nations. New Zealand ratified the CRPD in 2008.
- 5. Countries that have ratified the CRPD have an obligation to implement it. For economic, social and cultural rights in the CRPD, however, this can be through progressive realisation over time as resources allow.
- 6. The Strategy is our fundamental mechanism to establish priorities for working towards a non-disabling New Zealand by guiding the work of government agencies to identify and remove barriers that prevent disabled people from participating fully in New Zealand Society.
- 7. 'Non-disabling' is about removing the barriers in society that disable people-with impairments.

  This is considered to be stronger and more meaningful than 'enabling' which will only help disabled people get around barriers rather than remove them completely.
- 8. The Strategy can also be used as a tool to inform other organisations, including non-government organisations that make decisions on things that are important to disabled people. The Strategy was approved by Cabinet on 25 October 2016 [CAB-16-MIN-0550].

The Strategy was revised because there have been fundamental shifts in the way New Zealand and the world look at disability

9. The 2001 Strategy was revised, and the 2016 – 2026 Strategy developed because, although world leading at the time, the 2001 Strategy was no longer consistent with international and domestic developments, particularly the ratification of the CRPD in 2008.

The views of disabled people across New Zealand underpin the 2016 Strategy

- 10. The views of disabled people across New Zealand underpin the Strategy, and it has strong ownership by the disability sector. This has been achieved through two rounds of public consultation in 2016 with over 770 submissions and over 1130 people's attendance at workshops, focus group discussions and presentations.
- 11. The first phase of consultation was a 'blue skies' consultation, where disabled people, their whānau, supporters, service providers, Disabled People's Organisations (DPOs) and government agencies were asked what it would look like if disabled people were fully participating in New Zealand society, and what it would take to make that happen. The second phase of consultation sought feedback on the draft strategy by going back to the same people and places and asking whether the draft strategy reflected what they had told us.
- 12. In addition, ownership was fostered through the engagement of a Disability Strategy Revision Reference Group (the Reference Group)<sup>1</sup> representing a cross section of the disability sector, including representation from DPOs.

<sup>&</sup>lt;sup>1</sup> The New Zealand Disability Strategy Revision Reference Group members bring expertise and leadership in working within the disability sector, providing strategic advice, building connections between the government

13. This consultation and design process was seen as a positive example of how government agencies can work with the disability sector.

### The Strategy is underpinned by five key principles and approaches

- 14. Principles and approaches underpin the Strategy to help make sure all of the disabled community is visible, acknowledged and respected on an equal basis with others, and that disabled people can live a life with dignity and feel valued. Each of the principles and approaches also overlap, complement, or support each other. Three principles underpin the Strategy, these are:
  - Te Tiríti o Waitangi
  - The United Nations Convention on the Rights of Persons with Disabilities
  - Ensuring disabled people are involved in decision-making that impacts them. Disabled people are experts in their own lives and including them in decision making leads to better results. The CRPD also has a specific obligation on this in Article 4.

### The two approaches that underpin the Strategy are:

- Investing in entire lives a long-term, whole-of-life approach to ensure disabled people are more independent, can participate fully, contribute to communities and reach their full potential. This includes building evidence to ensure the right disability information and data (both qualitative and quantitative) are available at the right time to inform decisions and measure results. In the past disability has not been well recognised, counted or understood.
- Specific and mainstream services a twin-track approach to providing disability-specific supports and services as well as making sure mainstream services or supports are accessible to everyone, including disabled people. Ensuring that mainstream services are inclusive requires the:
  - provision of reasonable accommodations- reasonable accommodations are provided as a normal expectation, and not something that disabled people feel they have to request
  - incorporation of universal design the built environment, services, supports, and technologies seek accessible, understandable and usable design outcomes that work for everyone to the greatest extent possible without, or with only minor, adaptation.

### The Strategy has eight broad outcomes

- 15. The Strategy has a 10 year timeframe with eight broad outcome areas described from the perspective of disabled people and what achievement of the outcomes looks like from their perspective. Figure 1 illustrates the eight outcomes. Those outcomes are:
  - Outcome 1 Education "We get an excellent education and achieve our potential throughout our lives".

and the community sector and skill in collaborative approaches. The group includes members who bring the perspectives of Māori, Pasifika, older people, young people, families and service providers. They are Colleen Brown, Robbie Francis, Lance Girling-Butcher, Peggy Koopman-Boyden, Clive Lansink, Victoria Manning, David Matthews, Papaalii Seiuli Johnny Siaosi, Dr Martin Sullivan, Hamish Taverner, Johnny Wilkinson and Gary Williams. Reference Group members also include two representatives from government agencies. A representative from the Office of the Ombudsman observes each group meeting, on behalf of the Independent Monitoring Mechanism (made up of the Office of the Ombudsman, the Human Rights Comission and the Convention Coalition Monitoring Group).

- Outcome 2 Employment and Economic Security "We have security in our economic situation and can achieve our full potential".
- Outcome 3 Health and wellbeing "We have the highest attainable standards of health and wellbeing".
- Outcome 4 Rights protection and Justice "Our rights are protected, we feel safe, understood and are treated fairly and equitable by the justice system".
- Outcome 5 Accessibility "We access all paces, services and information with dignity and ease".
- Outcome 6 Attitudes "We are treated with dignity and respect".
- Outcome 7 Choice and control "We have choice and control over our lives".
- Outcome 8 Leadership. "We have great opportunities to demonstrate our leadership".
- 16. These descriptions inform identification of specific actions for implementation.

### The Disability Action Plan is the main mechanism for implementing the Strategy

- 17. The Disability Action Plan (the Plan) is the primary vehicle for implementing the actions to support the achievement of the Strategy. It presents priorities agreed by Cabinet for action that advance implementation of the CRPD and the Strategy. These priorities emphasise actions that require government agencies to work together, as well as with disability sector organisations and others.
- 18. As the Strategy is New Zealand's approach for implementing the CRPD in the New Zealand context, the plan will also help streamline government responses to international reporting on the CRPD.
- 19. The current Plan which covers the period from 2014 2018 was based on the previous strategy (2001) and the Concluding Observations from the United Nations Committee on the Rights of Persons with Disabilities at the New Zealand examination in 2014 [More detail is provided on the examination process in Appendix B].

### Good progress is being made through the current Plan

- 20. There are currently 28 actions in the Plan with good progress being made towards completion of the actions. The current status of actions (as at September 2017) is as follows:
  - 7 actions completed
  - 8 actions on track
  - 5 actions with minor risks to achieving milestones
  - 7 actions with major risks to achieving milestones
  - 1 action reinstated and being reassessed.
- 21. Further information about the Plan and the progress being made can be provided at your request.

### We propose that updating the Plan be informed by the Strategy and CRPD review process

- 22. The revised Strategy requires the Plan to cover four year periods and are refreshed at the mid-point to ensure priorities remain relevant (that is after two years). The current Plan finishes in 2018 and we would like the opportunity to discuss updating it with you. We think it will be important that any updated Plan aligns well with the new Strategy.
- 23. The next periodic review of New Zealand by the United Nations Committee on the Rights of Persons with Disabilities will begin in March 2018 when the Committee releases the List of

Issues that raises questions and requests additional information about implementation of the CRPD. There will be an opportunity to use these identified issues to inform the Plan update. Additional information about the periodic review process is attached as Appendix B.

### The Office for Disability Issues is leading the development of an "Outcomes Framework" because disabled people asked for accountability for implementing the Strategy

- 24. During consultation for the Strategy revision we were told that the previous strategy (2001) could have been improved by being better implemented and monitored.
- 25. Throughout 2017, ODI have been leading a co-design process with the disability sector and government agencies to create an Outcomes Framework by identifying potential Indicators for each of the outcomes in the Strategy so that progress can be monitored and reported and to create accountability for progress. Once complete, the Outcomes Framework would need to be approved by Cabinet. We welcome the opportunity to discuss the future of this work with you.
- 26. Subject to Cabinet approval we would propose that the final Outcomes Framework be incorporated into the Strategy document. Indicators and measures form the Outcomes Framework". It will:
  - provide a narrative to clarify the intent of each indicator
  - describe the measures for each indicator including the data source and the limitations
  - · identify who is responsible for collecting the data
  - · outline the frequency of reporting.
- 27. Where on-going work is required to develop measures for any of the final indicators, the Outcomes Framework could note that the measures are 'under development'. This has been seen in some international Outcome Frameworks where data is emerging.
- 28. In the Strategy it is specified that every year the Minister for Disability Issues will report to Parliament on the progress against the Outcomes Framework.

We are working with disabled people to develop indicators that are most important to them and which align to the Strategy

29. ODI has engaged with the Reference Group, relevant government agencies and the three Independent Monitoring Mechanism<sup>3</sup> partners (DPO Coalition, Human Rights Commission, Office of the Ombudsman) to develop and refine indicators. We currently have a draft set of 29 indicators that align well with the eight outcome areas of the Strategy (Appendix A), and would welcome your contribution.

It is important that indicators are reflective of what disabled people think will show progress, and are not limited by what is currently able to be measured

30. It is important that indicators are developed that show us whether the Strategy is being realised. To understand this, throughout this year we have worked with the disability

To date, this has been incorporated into the annual report presented to Parliament as required in the New Zealand Public Health and Disability Act 2000. ODI prepares this report.

The Independent Monitoring Mechanism (IMM) is responsible for providing an independent perspective on implementation of the Strategy. It was established by the Government in 2011 and fulfils an obligation for the Government under the CRPD to have an independent mechanism to promote, protect and monitor implementation under Article 33 of the CRPD. It is made up of the Human Rights Commission, Office of the Ombudsman and the DPO Coalition.

- community as they are best placed to know what is important to measure to determine progress.
- 31. This has meant that some of the 29 draft indicators are not currently being measured. We have provided information on which of the 29 draft indicators are currently being measured, which indicators have measures being developed, and which indicators are currently not being measured (Appendix A).

Existing and emerging data will provide measures for many of the indicators, however there are gaps

- 32. We currently have a large draft set of 29 draft indicators, which will involve substantial measurement. Some of the draft indicators are currently able to be measured through Stats NZ Surveys and administrative data held by government agencies.
- 33. Since 2015 the Disability Data and Evidence Working Group<sup>4</sup> (DDEWG) has been working on developing better data sources to understand the experience of disabled people in New Zealand and to contribute to effective policy and service development for disabled people. The Strategy and its outcomes provide an important framework for this work.
- 34. ODI met with the DDEWG on 5 October 2017 to commence discussions about the draft indicators that are not currently able to be measured.



- 36. We are continuing to work with Stats NZ and the DDEWG to establish measures.
- 37. We would like the opportunity to discuss with you the prospect of investing in creating new data sources.
- 38. It is important to note that there are strong expectations from the disability sector around measurement and accountability.

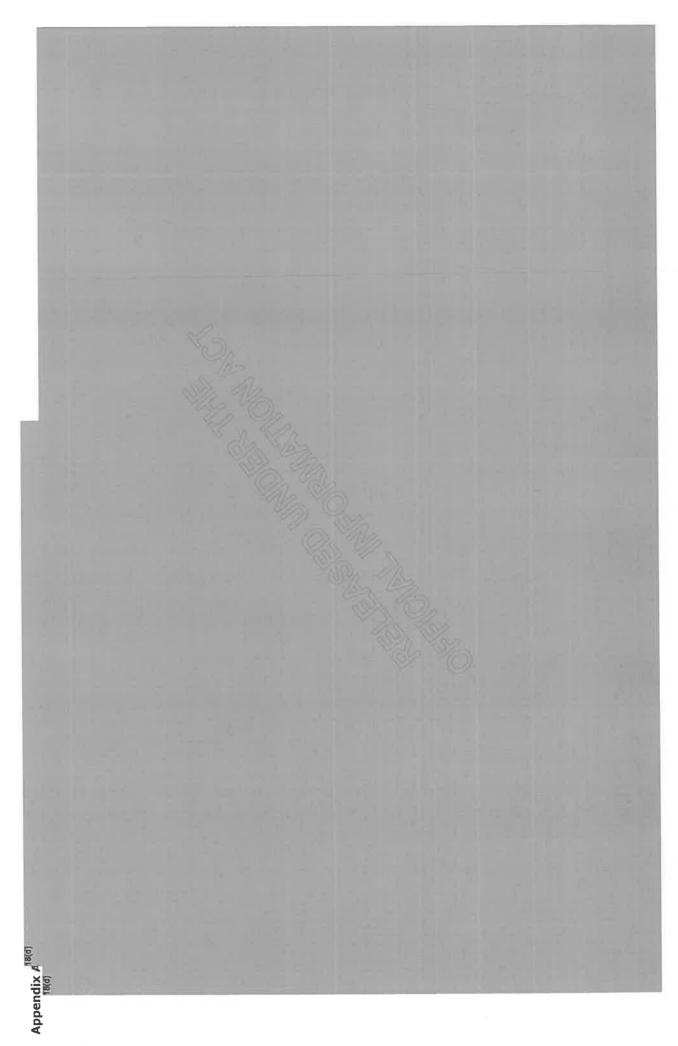
We are striving to measure change over the ten year course of this Strategy

39. As the importance of data and evidence has been emphasised in the development of the Strategy, it is vital that we establish some baseline measures soon, so that within the ten year timeframe of the new Strategy, we have the opportunity to view change over time. Hopefully, the data will indicate where positive change is occurring, and suggest where further work may be required.

### We propose to engage publically with disabled people to inform and explain the indicators and refresh the Disability Action Plan

40. Our initial plan was to undertake public consultation with disabled people on the indicators that have been developed. However, there are different options and we would like to discuss the approach with you.

<sup>&</sup>lt;sup>4</sup> A cross-agency working group involving disability sector representatives jointly led by Stats NZ and ODI.



# Appendix B New Zealand's review by the United Nations Committee on the Rights of Persons with Disabilities

- As a state party to the United Nations Convention on the Rights of Persons with Disabilities New Zealand is required to undergo a review process every four years on our progress with implementation. The last was held in 2014.
- The periodic review will begin mid-March 2018 when the List of Issues is provided to the New Zealand Government by the United Nations Committee on the Rights of Persons with Disabilites.
- The focus of the New Zealand Government's State Party report will be responding to the questions raised in the List of Issues.
- We currently understand that we will be required to submit a State Party Report by 28 October 2018.
- The IMM and any other civil society organisation can also submit reports to the United Nations Committee on the Rights of Persofis, with Disabilities to provide information about New Zealand.

