

# DISABILITY STOCKTAKE

February 2007



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## **Introduction**

The Disability Stocktake is part of the Programme of Official Social Statistics (POSS) led by Statistics New Zealand. The programme aims to provide a robust foundation for the development and evaluation of evidence-based social policy through improved measurement of New Zealand's social well-being. One important element of POSS involves investigating the potential for using administrative sources of data to produce official statistics.

The Disability Stocktake arose out of a need to gain a better understanding of administrative data on disability. This stocktake will help to identify gaps in available data. It will also assist the Office for Disability Issues (ODI) to monitor the implementation of the New Zealand Disability Strategy, and is consistent with objective 10 of the Disability Strategy, which is to “collect and use relevant information about disabled people and disability issues”. In addition, the Disability Stocktake is an initial step towards investigating the potential statistical uses of administrative data on disability and will also assist the redevelopment of the 2011 Disability Survey.

This report describes a selection of significant administrative data of possible relevance to those interested in disability in New Zealand. The contents of the dataset are briefly described, together with the eligibility criteria for inclusion. The eligibility criteria offer a look at the potential population covered by the dataset.

It is important to note that the resources identified here were created and are maintained for administrative purposes. The information can be collected for or as part of service delivery, an application, membership, regulation or registration. As such, the information is often not collected with regard to official statistics usage. Access to this data can be difficult or impossible, as agencies or databases may not be able to respond to ad hoc requests.

## **Scope of the Disability Stocktake**

The Disability Stocktake seeks information in administrative datasets about people with disabilities or a record of services to people with a disability. It is limited to electronic data held by government organisations. It excludes surveys, paper-based collections and administrative data held by non-governmental organisations, including community groups. No evaluation of the quality or range of the information held in administrative collections was conducted.

The ODI and a Statistics NZ reference group identified organisations likely to hold disability information. This process led to the identification of collections held by Veterans Affairs (VA), Housing New Zealand Corporation (HNZC), Ministry of Health (MoH), New Zealand Birth Defects Monitoring Programme (NZBDMP), Ministry of Education, Special Education and the Ministry of Social Development (MSD) are included here.

## **Summary of Findings**

A total of 19 datasets from six source agencies have been identified as containing information about people with disabilities. These datasets are summarised in the table below. Additional details about each of the datasets follow the table.

*Major National Disability-Specific Collections*

<b>Collection Name</b>	<b>Data Custodian</b>	<b>Duration</b>	<b>Collection Methods</b>	<b>Eligibility Criteria</b>	<b>Objective/Purpose</b>	<b>Selected Key Content</b>	<b>Accessibility</b>
Ministry of Social Development (MSD)	Ministry of Social Development PO Box 1556 Wellington New Zealand <a href="http://www.msd.govt.nz">www.msd.govt.nz</a>	Ongoing electronic information available beginning 1992, with some information not available until June 1996. Prior to 1992, some print materials are available	Application form and information obtained during management of a case	Vary substantially depending on the benefit in question. See: <a href="http://www.workandincome.govt.nz/publications/brochures.html#getting-financial-assistance">http://www.workandincome.govt.nz/publications/brochures.html#getting-financial-assistance</a>	To administer services, assistance and payments to those in need	Benefits administered include: Child Disability, Childcare Subsidy, Special Benefit, Special Needs Grant, Car Modification Funding, Home Modification Funding, Civilian Amputee Assistance, Residential Care Subsidy, Community Services Card, Veterans Benefits and the Accommodation Supplement	Not publicly available. Annual report, some published outputs. See: <a href="http://www.msd.govt.nz/work-areas/social-research/statistical-report.html">http://www.msd.govt.nz/work-areas/social-research/statistical-report.html</a>
RENTEL database	Housing New Zealand Corporation PO Box 2628 Wellington Tel: (04) 439 3000 <a href="http://www.hnzc.co.nz/">http://www.hnzc.co.nz/</a>	Ongoing since 2001	An initial enquiry form, an application form, and information provided by a health or disability professional and/or other support person(s) or agencies	Applicants eligible for the Suitable Homes Service and/or the Case Management Service	To provide background data about an applicant or existing tenant to assist the case manager in determining the present and future needs of a person with a disability	Household composition, disability, housing needs	Annual report, published outputs and customised tables may be possible (these may incur a charge)
Client Claims Processing System (CCPS)	HealthPAC (A business unit of the Ministry of Health) PO Box 1043 Wellington Tel: (04) 381 5308 <a href="http://www.moh.govt.nz">www.moh.govt.nz</a>	Ongoing since 1998	Data is collected using the Notification of Needs Assessment and Service Co-ordination Form	Those eligible for publicly funded health and disability services	The principal purpose of this data collection is to make payments	Needs assessment, primary disability, support package allocated	Not publicly available. Customised tables may be possible on request (these may incur a charge). There is no capability for meeting any increase in public demand for data from the CCPS

The New Zealand Birth Defects Monitoring Programme (NZBDMP)	New Zealand Birth Defects Monitoring Programme Ministry of Health PO Box 5013 Wellington <a href="http://www.moh.govt.nz">www.moh.govt.nz</a>	Ongoing since 1976	From cases admitted to a public hospital for treatment for a birth defect, or deaths in which a birth defect is diagnosed	Live births and stillbirths with a diagnosed birth defect at birth that is fatal or requires treatment in a hospital	To monitor the occurrence of birth defects in New Zealand. To investigate clusters of birth defects. To carry out research into the occurrence of birth defects in New Zealand	Birth weight/status, clinical code type, diagnosis/procedure description, birth/death location code	Annual report, and customised tables may be possible on request (these may incur a charge)
Ministry of Education, Special Education databases	Ministry of Education, Special Education PO Box 1666 Thorndon Wellington <a href="http://www.minedu.govt.nz">www.minedu.govt.nz</a>	Varies – mainly from 2000	Various administrative sources	See the Special Education section of the MOE website for Special Education policies and relevant application forms ( <a href="http://www.minedu.govt.nz/index.cfm?layout=index&amp;indexid=6871&amp;indexparentid=2107">http://www.minedu.govt.nz/index.cfm?layout=index&amp;indexid=6871&amp;indexparentid=2107</a> )	Used for internal business processes to provide services to students/families/facilities	Service information for individuals or facilities	Data is released only in accordance with the Privacy Act. Therefore, few datasets can be released to the public. See: <a href="http://educationcounts.edcentre.govt.nz">http://educationcounts.edcentre.govt.nz</a> for data that is available on the Education Counts website

## ***Ministry of Social Development***

By far the biggest collection of data related to disabilities comes from the Ministry of Social Development (MSD). MSD collects a wide range of information in the administration of benefits. Some of the benefits administered by MSD are available to individuals with disabilities or to caregivers supporting those with disabilities.

Initially, information is collected via an application form. As a benefit is administered, additional information may be recorded when a claim is validated, and further information may be collected as ongoing interaction takes place when a claim is managed. The types of information collected can vary a great deal depending on which benefits an individual applies for, which are received and the duration of the benefit. The database system at MSD is structured around an individual rather than a benefit, so the information on hand for any individual will vary depending on what benefits they have applied for and what information is collected for each benefit.

MSD's records are available electronically from 1992, with all records available from June 1996. Information prior to 1992 is available from published statistical reports. MSD releases annual reports that summarise some of the information held in its administrative database.

Because of the wide range of benefits offered by MSD and the common database used, the focus here is on describing individual benefits that are most likely to attract applicants with a disability. A description of each benefit and its eligibility requirements are presented as a rough measure of the population covered by a benefit. The information that exists on an individual within the database will vary greatly, as discussed above.

Services that may be delivered on specific grounds of disability include the following:

Sickness Benefit: This benefit is available to people who are temporarily off work or who are working less than usual due to sickness, injury, pregnancy or disability. The weekly payment amount depends on the applicant's personal situation. To receive a Sickness Benefit the client must:

- not be in full-time work, be willing to undertake it, but because of sickness, injury or disability, be limited in his or her capacity to seek, undertake or be available for full-time employment or
- be in employment but losing earnings through sickness or injury, not actually working or be working at a reduced level
- be aged 18 years or older or
- be aged 16 years or older, married or in a civil union and have one or more dependent children
- have continuously lived in New Zealand for two years or more
- have no income or an income of less than the amount that would fully abate the benefit.

To receive a Sickness Benefit on the grounds of hardship, the client must meet the first four of the above criteria, but have lived in New Zealand for less than two years and be suffering hardship. A Sickness Benefit can also be granted on the grounds of hardship if a client meets the hardship criteria and:

- is single and aged 16 or 17 years and
- is either pregnant or undergoing treatment in a recognised rehabilitation programme.

Invalids Benefit: This benefit is to help meet living costs if the applicant is unable to work due to a permanent sickness, injury or disability. To qualify for an Invalids Benefit the client must:

- be 16 years old or over and
- have lived in New Zealand 10 years or more and
- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- be ordinarily resident in New Zealand on the date of application and
- be permanently and severely restricted in their capacity for work because of sickness, injury or disability, or be totally blind.

All the qualifications for age, residency and medical must be met to receive an Invalids Benefit. “Permanent” means that the sickness, injury or disability is expected to continue for at least two years, or a terminal illness where the client is not expected to live more than two years. “Severely” means that a person cannot regularly work 15 hours or more per week in open employment. Open employment is any employment other than sheltered employment.

Domestic Purposes Benefit – Care of Sick or Infirm: This benefit provides income support for clients who are caring full time at home for someone (other than their partner) who would have to receive hospital care if they were not being cared for at home.

To get a Domestic Purposes Benefit – Care of Sick or Infirm the client must:

- be 16 years or older
- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- generally be ordinarily resident in New Zealand.

A client applying for a Domestic Purposes Benefit – Care of Sick or Infirm must provide full-time care and attention to a person (other than their partner) at home.

Note that the Domestic Purposes Benefit – Care of Sick or Infirm can be paid to a parent who is required to provide full-time care and attention at home to their dependent child who would otherwise need hospital care.

Although married or civil union couples can apply for the Domestic Purposes Benefit – Care of Sick or Infirm, there is no married or civil union rate of benefit. The partner will need to qualify for a benefit in their own right or have some other form of income.

War Pensions: The War Disablement Pension is awarded to ex-service people who have a disability as a result of their military service. The War Disablement Pension is a non-taxable, non-income-tested pension (if living in New Zealand) and is assessed according to the degree of disablement. To qualify for a War Disablement Pension the

applicant must currently be suffering from a disability that was caused while serving in one of the following forces:

- New Zealand forces in an overseas war or emergency or in regular service before 1 April 1974
- New Zealand Mercantile Marine during World War II
- Mercantile Marine of another Commonwealth country during World War II – as long as the applicant lived in New Zealand immediately before the war
- forces of another Commonwealth country during a war or emergency as long as the applicant lived in New Zealand immediately before the war or emergency
- Emergency Reserve Corp.

The Surviving Spouse Pension is a compensatory award for the partners of ex-service people who have died as a result of a disability or medical condition attributable to their service with the New Zealand Armed Forces.

Disability Allowance: The Disability Allowance covers additional costs directly related to the person's disability. The amount paid is estimated in relation to the actual costs that have been or will be incurred on a regular basis.

The Disability Allowance can be paid to help people (or their partner or dependent children) with disabilities to meet costs that are:

- regular and ongoing
- a direct result of a disability that is expected to continue for at least 6 months
- additional to or over and above those costs that a person without a disability would have
- not fully funded by another agency such as health, ACC or other accident insurers; education or regional councils and
- not a residential care service.

To be able to receive a Disability Allowance a client must:

- meet an income test
- have a disability that is likely to last at least 6 months
- have ongoing, additional costs arising from that disability
- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- generally be ordinarily resident in New Zealand
- be receiving an income-tested benefit or meet the appropriate income limit, and a person must be assessed by a registered medical practitioner or specialist as having a disability:
  - that is likely to last at least six months or
  - have a life expectancy of less than six months because of a terminal illness.

The person's disability must mean that they have a reduction in independent functioning to the extent that they need:

- ongoing help with normal living tasks or
- ongoing supervision or treatment from a registered health professional.

The person must also be assessed as having ongoing, additional costs arising directly from that disability, and that other assistance available to meet those costs is insufficient to cover them. A Disability Allowance is not granted to a client just because of their age. However, an older person may have an age-related disability.

Child Disability Allowance: The Child Disability Allowance is a non-taxable allowance that is available to the principal caregiver of a dependent child who has a serious disability. It is paid because of the extra care that may be needed by a child who has a physical, sensory, psychiatric or intellectual disability. The client may also be able to receive a Disability Allowance to meet any additional costs the child has because of his or her disability. There is no income and asset test for the Child Disability Allowance.

Once a child turns 16 years of age they may be able to receive an Invalids Benefit. To be able to receive a Child Disability Allowance a client must:

- generally be aged 16 years or over
- be the principal caregiver of a dependent child with a disability (or if there is no principal caregiver have the care and control of the child for the time being)
- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- generally be ordinarily resident in New Zealand.

In addition to this the child must:

- generally be ordinarily resident in New Zealand
- be a dependent child
- have a physical, sensory, psychiatric or intellectual disability
- need constant care and attention because of the disability
- be likely to need care permanently or for more than 12 months and
- meet the required living arrangements.

Childcare Subsidy: The Childcare Subsidy is a non-taxable payment that aims to assist low-income clients who have dependent children to undertake and remain in employment, education or training. It also assists clients' access to preschool care if they or their child are seriously disabled or ill.

A client may be able to receive assistance for subsidised childcare of up to nine hours a week if:

- they are the principal caregiver of a dependent child
- they meet an income test
- the child is aged under five years old, or under six years old if the child is one for whom a Child Disability Allowance is paid, or aged five years but not yet attending a school (Childcare Subsidy payable for four weeks after the child turns five years old)
- the child attends a licensed preschool facility
- the child attends for at least three hours per week
- they are a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- generally be ordinarily resident in New Zealand.

The rate of payment of the Childcare Subsidy depends on the number of children and the level of income of the client. The Childcare Subsidy is paid directly to the preschool facility that the child attends on a weekly basis. Payment must not be more than the fee the preschool facility charges (including the fee charged to keep the child's place open), and for no more than 50 hours a week. The number of hours attended by the child must be calculated on a weekly basis.

Special Benefit: The Special Benefit is a discretionary, non-taxable benefit. Its intent is to provide short-term assistance to clients whose particular circumstances are causing hardship. A client does not need to be receiving a benefit in order to be granted the Special Benefit. There is no time limit on the Special Benefit if payment continues to be justified. However, a Special Benefit is not intended to be a long-term solution to a client's financial shortfall unless the client's individual circumstances justify this. Instead, it is paid to help clients to meet their essential living costs while they make efforts to reduce their commitments and live within their usual income. The granting of a Special Benefit is discretionary and made only where justified.

For a client's circumstances to warrant payment they generally must:

- meet a cash asset test
- have an ongoing, reasonably substantial deficiency of income over expenditure and commitments
- have expenses that are essential and not reasonably avoidable
- have no other means of financial assistance or resources to reduce their deficiency
- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or here on a temporary permit) and
- generally be ordinarily resident in New Zealand.

There is no maximum amount payable for the Special Benefit. Where it is practical, the client should receive appropriate advice with the objective that, wherever possible, the need for Special Benefit is reduced or eliminated within six months. This is required particularly where the rate of payment is over \$50.00 per week. The Special Benefit can be paid as a lump sum and/or as an ongoing payment.

As the Special Benefit is generally intended to be short-term assistance, any payments made are reviewed three months after the grant and then at six-month intervals to assess ongoing need for the Special Benefit and any steps that may be taken to reduce the need for it.

Special Needs Grant: Special Needs Grants provide non-taxable, one-off recoverable or non-recoverable financial assistance to clients to meet an immediate need for urgent necessary items. A client does not have to be receiving a benefit to qualify for Special Needs Grants.

In order to receive a Special Needs Grant a client must:

- meet an income and asset test
- have an essential need, emergency need or require payment for specific circumstances
- not be able to meet the need from their own resources or through other sources

- be a New Zealand citizen or permanent resident (i.e. not be in New Zealand unlawfully or on a temporary permit) and
- generally be ordinarily resident in New Zealand.

Clients must provide proof of their income and assets (for example current payslips and bank statements). Recoverable Special Needs Grants must be paid back.

Special Needs Grants are available for emergency medical equipment. However, unless exceptional circumstances exist, the maximum amount payable towards emergency medical equipment is \$200.00. Although Special Needs Grants under this category may be recoverable or non-recoverable, generally grants for emergency medical equipment are non-recoverable. However, if it is considered equitable in the circumstances for the client to pay the grant back, Work and Income may decide that the Special Needs Grant should be recoverable.

Work and Income has confirmed that it is possible to receive more than one Special Needs Grant within a 12-month period. In addition, it is possible to receive more than one Special Needs Grant for medical equipment within a 12-month period. For the latter to happen, a person must meet all of the criteria each time they apply, i.e. they must prove that the equipment cannot be funded through their district health board (DHB) and that they have no other way of meeting the cost etc.

Car Modification Funding: Car Modification Funding is paid by an MoH contracted provider and offers funding for people with serious disabilities, to enable them to purchase or convert a car. This is to allow them to retain or obtain full-time employment or undertake voluntary work of more than 20 hours per week. They must also be unable to use or access public transport. Work and Income administers the Income and Asset Test. A client does not have to be receiving a benefit to qualify for Car Modification Funding.

To be able to receive Car Modification Funding, the client must have been needs assessed as requiring the car by an MoH contracted provider. Assessments for car modifications are carried out by an occupational therapist. All applications are subject to some form of income and asset testing. The maximum amount payable to purchase a car is \$11,970.00. The maximum amount payable for Car Conversion Funding is \$965.00. Applicants can receive both amounts. When assessing a client's income and assets to see whether they qualify for Car Modification Funding, the income and cash assets of the person with the disability and the partner of the person with the disability are taken into account. There is an income exemption amount of \$40,000.00. There is a cash assets exemption amount of \$4,500.

Home Modification funding: Home Modification Funding is paid by an MoH contracted provider and offers funding for people with serious disabilities to enable them to have essential alterations made to their home, to meet their specific needs. A client does not have to be receiving a benefit to qualify for Home Modification Funding.

To be able to receive Home Modification Funding the client must have been needs assessed as requiring the alterations by an MoH contracted provider. Assessments for house modifications are carried out by an occupational therapist. The contracted

provider decides whether the client meets the qualifications for funding. Work and Income administers the Income and Asset Test. All applications are subject to some form of income and asset testing. There are different tests for different funding levels. For applications up to \$200 no income test is applied, but cash assets must not be more than four times the appropriate Invalids Benefit rate. For applications between \$201 and \$7,900 no income or asset test is applied. For applications over \$7,900 an income and asset test is applied only with regard to the amount over the \$7,900 level.

Civilian Amputee Assistance: People who have attended an artificial limb centre can be reimbursed for the costs incurred in attending a centre. These costs can include travel, accommodation, meals, loss of earnings and an attendant. If the client lost a limb due to an accident and they qualify for assistance from ACC, they will not qualify for assistance from Work and Income.

This assistance is available to ensure that people are not prevented from attending an artificial limb centre to have an artificial limb adjusted or repaired because they are unable to meet the cost of travel and accommodation. It applies equally to amputees or people who were born without a limb. This assessment is not subject to an income or asset test. To be able to receive travel and/or accommodation assistance for attending an artificial limb centre a client must:

- have applied for reimbursement within six months of attendance at the artificial limb centre and
- provide proof of their attendance at an artificial limb centre and
- provide receipts of their costs.

A client should complete the Application by Civilian Amputee for Reimbursement Form and provide an appointment card or certificate of attendance from the artificial limb centre.

Residential Care Subsidy: This subsidy is available if long-term residential care in a rest home or hospital is needed. Residential Care Subsidy provides financial assistance to an eligible person who:

- has been needs assessed as requiring long-term residential care in a hospital or rest home indefinitely
- is receiving contracted care services from a service provider and
- has been means assessed and is found to have assets at or below the relevant threshold.

Work and Income is required to assess the assets and income of clients who apply for Residential Care Subsidy. This means assessment helps to determine whether the client is financially eligible for the Residential Care Subsidy and assess how much the client must contribute to the cost of their care.

The Residential Subsidy Unit performs the financial means assessment. The MoH assesses all other aspects of a client's eligibility and pays the Residential Care Subsidy to the client's rest home/hospital. The MoH determines all aspects of eligibility for Residential Care Subsidy other than the client's financial eligibility. For a client to be eligible they must:

- be aged 65 years or over or

- be aged between 50 and 64 years, unmarried and have no dependent children and they must:
- be eligible for publicly funded health and disability services and
- have been needs assessed as requiring long-term residential care in a hospital or rest home indefinitely and
- be receiving contracted care services from a service provider.

Clients who are aged 65 years and over must also undertake a means assessment of their assets. If their assets are at or below the relevant asset threshold, then they are financially eligible for the Residential Care Subsidy. They then undergo a means assessment of their income to determine the contribution they must make towards the cost of their care.

Clients who are aged 50 to 64 years, unmarried and have no dependent children are not required to pay for their care out of their assets, so they do not undergo a means assessment of their assets. However, they do undergo a means assessment of their income to determine the contribution they must make towards the cost of their care.

Community Services Card: The purpose of the Community Services Card is to help individuals and families on low to modest incomes with the costs of health care, by providing subsidies on doctors' fees and prescriptions. The current subsidy levels for each visit are \$15.00 for adult visits to the doctor and \$20.00 for a child aged 6 years or over.

Community Services Card holders pay only \$3 for a subsidised prescription item, but still have to pay the manufacturer's premium if there is one. The amount of the prescription charge and the premium can change. There is no government prescription charge on items for children aged under six years, although there may still be a manufacturer's charge on some items, which the card holder may have to pay.

The Community Services Card does not entitle holders to subsidised visits to private health professionals, including specialists, osteopaths, podiatrists, dieticians etc. To receive the card an individual must:

- be 18 years old or over (some 16–17 year olds may also get it) and
- have a low to middle income or be getting one of our main types of income support and
- be a permanent legal resident of New Zealand and normally live here. People who have refugee status, or have applied for refugee status, may also apply for a card.

Cardholders can also use their Community Services Card for their dependent children under the age of 18 years.

### ***Housing New Zealand Corporation***

The RENTEL database is the HNZC database that records information about all HNZC's applicants, tenants and properties. This is the only HNZC database in which administrative data on disability is held about the two specialist services delivered by

HNZC for people with disabilities: the Suitable Homes Service and the Case Management Service.

*Collection description:* The Suitable Homes Service is a service to help people with physical disabilities into a modified home that meets their requirements. Applicants do not need to be HNZC tenants to access this service. HNZC can help by finding an already modified HNZC property, or it can assist with modifications to an existing private or rental home by putting clients in contact with the agencies that help fund modifications.

*Eligibility criteria:* When determining an applicant's eligibility for HNZC housing, the corporation will consider their residency status and whether an applicant and other members of a household ordinarily and lawfully live in New Zealand, their income, assets and level of need, as well as those of their partner.

The eligibility criteria for the Suitable Homes Service state that the applicant must have a long-term disability lasting longer than six months, and that the applicant must require structural modifications to a home to be able to live there safely and independently.

*Collection description:* The Case Management Service is for people with a persistent, significant and complex housing need, including those with a mental illness, older people, people with an intellectual disability, people with a dual diagnosis, people recently released from prison who have special needs, and families with special needs other than those listed.

*Eligibility criteria:* These require that the applicant must have significant, persistent and complex unmet need that affects their ability to sustain and retain adequate suitable housing, and that the applicant must be referred to this service by a professional. Criteria regarding personal and family residency status, income, assets and the level of need of applicant and partner, as mentioned above, also apply.

### ***Ministry of Health***

*Collection description:* The Client Claims Processing System (CCPS) processes payments for support services on behalf of both the MoH and DHBs. The system holds only payment-related client data and, depending on the service, has client-based payment history dating back to 1998. CCPS is administered by Health PAC (Health Payments, Agreements and Compliance), a business unit of the MoH.

The MoH is in the process of developing a new national database that will be better able to provide much more comprehensive information, particularly regarding service and client characteristics for planning and reporting purposes. The new national system will be implemented by August 2007.

*Eligibility criteria:* A client must be eligible for publicly funded health and disability services (i.e. a New Zealand citizen or normally resident within New Zealand), and must also:

1. meet the ministry's definition of disability:

“A person must be assessed as having a physical, intellectual, sensory, psychiatric<sup>1</sup> or age-related<sup>2</sup> disability, or a combination of these, where the disability is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that the person needs ongoing support”

2. be assessed by the appropriate agency, for example a Needs Assessment and Services Coordination (NASC) agency, as requiring publicly funded disability support services. The NASC determines the service and the level of service the client can access.

To access environmental support services (ESS) the person must be assessed by an accredited specialist assessor. Note that there are further access and eligibility criteria specific to different types of supports.

There is little capability to meet any increase in public demand for data from CCPS.

### ***New Zealand Birth Defects Monitoring Programme***

*Collection description:* The New Zealand Birth Defects Monitoring Programme's (NZBDMP's) ongoing data collection started in 1976. Captured data is reported annually and included in the annual report of the International Clearinghouse for Birth Defects Surveillance and Research. The data collection aims to monitor the occurrence of birth defects in New Zealand and investigate clusters of birth defects, for the purpose of research into the occurrence of birth defects in New Zealand.

NZBDMP receive its information from hospitals and cause of death notification. An annual report is produced, and customised tables may be available on request. However, these could incur a charge. Annual data is also published in the annual report of the International Clearinghouse for Birth Defects Monitoring Systems at [www.icbd.org](http://www.icbd.org).

*Eligibility criteria:* Cases are ascertained from live births and stillbirths with a diagnosed birth defect that is fatal or requires treatment in a hospital.

### ***Ministry of Education, Special Education***

*Collection description:* Ministry of Education, Special Education is a branch of the Ministry of Education, providing services to children and young people with special education needs. Data is collected from administrative operations, the majority of

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<sup>1</sup> Devolution of disability support services funding for psychiatric disability to district health boards (DHBs) began in 2001 and was completed in 2003. This means that DHBs are now responsible for providing long-term mental health support services for people with psychiatric disability. The responsibilities of DHBs are outlined in the Mental Health Drug and Alcohol Services section of the ministry's service coverage schedule.

<sup>2</sup> Age-related disability support services have been provided by DHBs since services were devolved from the Ministry of Health in 2003. The Ministry of Health retains services for people with long-term disabilities (largely under the age of 65 years) and some national contracts.

which dates back to 2000. The database contains information related to the Ministry of Education, Special Education mission, which is the provision of extra help, adapted programmes, learning environments, or specialised equipment or materials to support children and young people with their learning and to help them participate in education.

*Eligibility criteria:* This varies; assessment is often undertaken by school teachers and staff as to a child's/young person's eligibility. The types of support required by the child are also a factor of the assessment process.

## APPENDIX

### What is Administrative Data?

Administrative data is information resulting from the interactions of individuals and groups with government departments. The administrative data of interest to this stocktake are records of clients in agency programmes providing services for disabled people. The information can be collected for or as part of service delivery, an application, membership, regulation or registration. For example, administrative records are maintained to regulate the flow of goods and people across borders, respond to the legal requirements of registering births and deaths, and administer benefits such as pensions or obligations like taxation. As such, the information is typically collected with a specific administrative purpose in mind, without regard to its statistical use.

Most administrative datasets tend to collect personal information such as name, address, phone number and age. This information tends to be the most universal and of best quality since it is very important for administrative purposes. Databases tend to collect additional information that is critical to the administration of a programme; this varies considerably and is specific to programme needs.

There are several major potential benefits in using administrative data for statistical purposes. First, the datasets already exist, so they do not need to be collected. Additionally, coverage with administrative data can be very good since it may contain entire populations rather than just a sample of a population. Finally, there are significant cost advantages achieved when working with an existing dataset and there is much less burden placed on respondents.

Although there are benefits from drawing statistics from administrative systems, there are also risks. Often, the potential statistical uses of administrative records were unknown when the programme gathering records was implemented. For that reason, the benefits need to be balanced against the risks. The main areas of weakness or risk are summarised below.

*Quality:* The quality of data from administrative sources in terms of the relevance of the concepts, completeness, consistency and accuracy may not meet the standards required for official statistics or for researcher needs.

*Coverage:* Administrative records may not accurately represent the population of interest, leading to issues similar to sampling and non-response bias. This is particularly an issue for collections that are voluntary in nature.

*Keeping information up to date:* There are difficulties in keeping administrative data up to date, particularly where the data is not essential to the administration of a collection. For example, driver's licences and passports do not contain up-to-date address and marital status information.

*Unit of measurement:* Administrative data is often event or case based rather than person based, which sometimes makes the generation of statistics based on the individual as the unit of analysis problematic. Even where person-based data is available, it is often difficult to aggregate administrative records to larger units of policy interest, such as the family or household.

*Continuity:* Administrative data collections are subject to change as a result of administrative, policy or technical decisions, impairing the stability and usefulness of the data over time.

*Documentation:* There is often poor documentation associated with administrative data, rendering interpretation of the data difficult and making it problematic for users to judge its fitness for purpose.

*Privacy concerns:* The use of administrative data may raise concerns about the privacy of the information in the public domain, especially when the administrative records are linked with other sources of data.

*Fragmented:* As by-products of separate systems, the statistics generated from administrative data sources often do not use standard classifications and coding systems.

*Access, availability and awareness:* Data from administrative sources is often unused by both researchers and the public and private sectors because of difficulties in accessing it. There is also a lack of understanding about what information is collected and how it can be obtained.

*Geography:* Administrative data is often produced for administrative areas, such as police districts or health districts. Often, it cannot be broken down to smaller levels or cannot be combined easily with data from other sources.

*Data management:* The absence of consistent standards across government agencies in relation to the management of administrative data can make the process of using administrative data for statistical purposes more complex, particularly where integration of administrative datasets is required.<sup>3</sup>

## **Processes Applied to the Stocktake**

A list of known and potential data custodians was compiled on the basis of information provided by stakeholders. Agencies on this list were contacted to determine whether they held databases likely to contain information relevant to the stocktake. Those agencies that appeared to have relevant databases were asked to provide more detailed information by completing a questionnaire focusing on specific characteristics and aspects of the databases. The characteristics and aspects were determined based on previous projects that Statistics NZ has undertaken on

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<sup>3</sup> This section on administrative data is based on a report by Denise Brown, Principal Social Statistician, *Programme of Official Social Statistics: Administrative Data Scoping Report*, Statistics New Zealand (unpublished).

administrative data, and with a view to extending the work already undertaken by the ODI.

The topics and the questionnaire were peer reviewed within Statistics NZ. Comments on the questionnaire were also sought from the ODI. Separate meetings were held with the MSD, GSE, MoH and ACC in order to elicit their feedback on the questions and to determine whether they would be able to answer them. Those four organisations were selected because they hold the largest collections of administrative data on disability. As a result of feedback from those organisations, the questionnaire was modified and refined before being emailed to respondents for completion during the first week of December 2005.

The questionnaire was emailed to the MSD, ACC, MoH, GSE, VA, the NZBDMP, the HNZA and the State Services Commission (SSC). Other government departments, including the Department of Labour, the Ministry of Justice, the Ministry of Transport and the New Zealand Health Information Service, had earlier advised that they did not hold administrative data on disability. As a consequence, those organisations were not asked to complete the Disability Stocktake questionnaire.

Responses were received from all organisations except ACC. The SSC's response has not been included in the Disability Stocktake because there were problems with the quality of data collected on the disability status of public servants. The SSC has now ceased collecting this information.