



17 March 2025

Tēnā koe

### **Official Information Act request**

Thank you for your email dated 16 February 2025 in which you requested information about the criteria the Ministry of Social Development (MSD) and Needs Assessment and Service Coordination (NASC) organisations use to determine a person's eligibility for Ministry-funded disability support services.

I have considered your request under the Official Information Act 1982 (the Act) and have decided to grant it in full. Please find attached the following documents in scope of your request:

- *Appendix One – MSD DSS Operational Policy DSS Eligibility (DRAFT)*
- *Appendix Two – Operational Guideline for the Assessment of Intellectual Disability to Access DSS Contracted for People with Intellectual Disability in NZ 2021*
- *Appendix Three – Practice Note – ASD Diagnosis*

Two excerpts are also provided as a significant amount of information in the original document is considered out of scope of your request (section 16(1)(e) of the Act refers). Please find these attached:

- *Appendix Four – Excerpt from Operational Manual for NASC Managers Vol 1 – Disability Services Directorate – MOH*
- *Appendix Five – Excerpt from Operational Manual for NASC Managers Vol 2 (Appendices) – Disability Support Directorate - MOH*

As you may be aware, responsibility for the administration of funding for disability support services transferred to a branded business unit within MSD in September 2024. Prior to that, responsibility for the administration of disability support services funding sat with the Ministry of Health (MOH) and the Ministry of Disabled People. For this reason, some of documents provided were published by the MOH's Disability Support Services Directorate and include MOH branding. Apart from branding, these versions of the documents are the ones used by MSD.

MSD will update the content of these documents to reflect any changes to eligibility criteria for disability support services as and when required.

**Publicly available information**

Some information within scope of your request is publicly available at the links below:

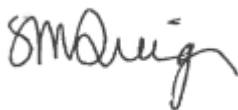
- Disability Support Services Operational Policy – Eligibility  
<https://fyi.org.nz/request/28659/response/113273/attach/3/OIA3500%20Documents.pdf>
- How to access support - [www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/how-to-access-support](http://www.disabilitysupport.govt.nz/disabled-people/assessment-and-funding/how-to-access-support).

I will publish this decision letter, with your personal details deleted, on the Ministry's website in due course.

If you wish to discuss this response with us, please feel free to contact [OIA\\_Requests@msd.govt.nz](mailto:OIA_Requests@msd.govt.nz).

If you are not satisfied with my decision on your request, you have the right to seek an investigation and review by the Ombudsman. Information about how to make a complaint is available at [www.ombudsman.parliament.nz](http://www.ombudsman.parliament.nz) or 0800 802 602.

Ngā mihi nui

pp. 

Anna Graham  
**General Manager**  
**Ministerial and Executive Services**

# MSD Disability Support Services Operational Policy

## Disability Support Services Eligibility

<b>Date inherited from Ministry of Health:</b>	01/07/2022
<b>Internally reviewed by:</b>	Tigga Taylor, Advisor Operational Policy, DSS; Rebecca Livingston, Senior Advisor Operational Policy, DSS
<b>Sponsor:</b>	Anne Shaw, Associate Deputy Chief Executive, DSS
<b>Date reviewed:</b>	13/12/2024
<b>Date of future review:</b>	13/06/2026
<p>Whaikaha – Ministry of Disabled People inherited this operational policy from the Ministry of Health when Whaikaha was established on 1 July 2022. From 16 September 2024, the Disability Support Services business group, within the Ministry of Social Development, is now responsible for this policy.</p> <p>We have adjusted the language, roles, and responsibilities in this policy to reflect these changes. <b>Please note that Disability Support Services will be undertaking a more substantive review of this policy in the future.</b></p>	

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## Purpose

The purpose of this operational policy is to define eligibility for disability support services funded by Ministry of Social Development (**MSD**) Disability Support Services (**DSS**). This policy is intended to support Needs Assessment and Service Coordination organisations (**NASCs**) contracted by DSS to apply a nationally consistent approach to implementing eligibility criteria.

This operational policy explains the process for eligibility determination, presents the definitions of physical, sensory, and intellectual disability and clarifies cross-funder relationships.

The policy also includes information about the NASC process, high level guidance for NASCs on funding relationships with Health New Zealand | Te Whatu Ora (**Health NZ**) and descriptions of the disability support services that can be accessed without a NASC assessment.

This operational policy is for DSS and NASCs.

This operational policy must be read in conjunction with the:

- '**Operational Policy and Guidelines 2024/25**: Freeze on residential care funding and management of NASC indicative budgets and EGL site fixed budgets'.
- Through this policy, MSD DSS is actioning fiscal sustainability recommendations from the 2024 Independent Review of disability support services. The above policy implements a freeze on residential service admissions and mandates using prioritisation and overarching criteria for service access, funding access, and funding increases.

## Scope

This is a national operational policy.

## Background

In 1992, under the "New Deal"<sup>1</sup> the Government realigned responsibilities and funding for disabled people and tāngata whaikaha Māori (**tāngata whaikaha**). Between 1993 and 1995 most Department of Social Welfare disability-related programmes and services progressively transferred and were consolidated with existing Ministry of Health (**MoH**) services under the regional health authorities (**RHAs**) and Vote: Health. The basis of access to services was shifted from

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<sup>1</sup> *The New Deal: Support for Independence for People with Disabilities*, Ministers of Social Welfare and Health, 1992.

nationally specified 'entitlements' to individually assessed needs, within available or capped funding.

In 1994, The New Zealand Framework for Service Delivery (the DSS Framework) was put in place by the RHAs under MoH's direction. Under the DSS Framework, to access a range of MoH funded support services, an individual had to first meet MoH's definition of disability, and then have their needs assessed and undergo service coordination or planned allocation of services, within available resources. Assessment and allocation of services required an auditable separation from the provision of services, which in most instances was by contracted providers.

The definition of an eligible person was outlined in the Government's definition of a 'person with a disability' for the purpose of accessing disability support services [CAB (94) M 3/5 (1a)] (see [Appendix 1: Definitions](#)).

People identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) fell under the 1994 definition.

Since the 1994 definition the responsibility and funding for psychiatric<sup>2</sup> and age related<sup>3</sup> disability was devolved to District Health Boards<sup>4</sup>. There has been further clarification of responsibility and funding for people with Long Term Support needs resulting from Chronic Health Conditions<sup>5</sup> (**LTS-CHC**) and people diagnosed with Autism Spectrum Disorder (**ASD**)<sup>6</sup>.

Responsibility and funding for people with physical, sensory, and intellectual disabilities remained with MoH.

From 1 July 2022, responsibility and funding for these groups of people moved to Whaikaha — Ministry of Disabled People (**Whaikaha**). From 16 September 2024, DSS and related funding and service delivery responsibilities were transferred from Whaikaha to the new DSS business unit within MSD<sup>7</sup>.

## Service description

Eligibility means the right to be considered for publicly funded health and disability services. It is not an entitlement to receive any particular service. If a person wishes to access disability support services funded by DSS, they are required to meet access criteria. If a person is not eligible for publicly funded

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<sup>2</sup> Devolved 2001.

<sup>3</sup> Devolved 2003.

<sup>4</sup> Health NZ was established on 1 July 2022 and took over the responsibilities and services previously provided under the District Health Board (DHB) structure.

<sup>5</sup> Devolved to DHBs in 2011.

<sup>6</sup> Clarification that disability related support needs resulting from ASD may be supported through MoH DSS from 2014.

<sup>7</sup> See [Improving the sustainability of Disability Support Services | Whaikaha](#).

services<sup>8</sup>, they are liable for the full cost of the services they receive and will access these independently.

## Service access

Most disability support services funded by DSS are accessed through NASCs. A list of NASCs can be found on the DSS website<sup>9</sup>.

### Process for determining eligibility

To be considered for most disability support services<sup>10</sup> funded by DSS, a disabled person may self-refer or is referred to a NASC contracted by DSS.

The NASC screens the referral<sup>11</sup> to confirm that the disabled person referred:

- can be considered for the full range of publicly funded health and disability services under the current Eligibility Direction<sup>12</sup>
- is likely to meet the Government's definition of a 'person with a disability' for the purposes of accessing disability support services ([CAB \(94\) M 3/5 \(1a\)](#)) (see [Appendix 1: Definitions](#))
- is likely to have a physical, sensory, or intellectual disability, or a combination of these **after** provision of equipment, treatment, and rehabilitation
- does not have an injury that is likely to meet ACC's cover and entitlement criteria under the Accident Compensation Act 2001<sup>13</sup>.

The NASC may request a specialist assessment or clinical reports to help confirm eligibility for disability support services funded by DSS.

If a person meets the above criteria, this triggers a needs assessment to confirm that they meet the criteria to receive disability support services funded by DSS.

### Disability support services inclusions funded by MSD DSS

DSS funding for disability support services includes disabled people who:

- are eligible for publicly funded health and disability services

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<sup>8</sup> Refer [Eligibility explained on Health NZ website](#)

<sup>9</sup> See [Needs assessment services | Disability Support Services](#).

<sup>10</sup> Refer section Other Information – DSS that do not require a NASC assessment.

<sup>11</sup> This is the general practice; however, some NASCs move directly to determining eligibility at the time of the needs assessment.

<sup>12</sup> Refer [Eligibility for publicly funded health services](#).

<sup>13</sup> Some people are eligible for supports from both DSS and ACC, such as those with pre-existing disabilities who have an accident that results in additional support needs. DSS funds supports received for any pre-existing disability. Where it is too difficult to determine which support needs are due to a pre-existing disability and which to an accident, a pragmatic joint funding/shared services arrangement will be negotiated.

- present for assessment for DSS before the age of 65
- have a physical, sensory, or intellectual disability or a combination of these, which is likely to:
  - remain even after provision of equipment, treatment and rehabilitation
  - continue for at least six months, and
  - result in a need for ongoing support.
- do not meet the exclusion criteria (refer to section [DSS disability support services funding exclusions](#)).

In addition, DSS funds Environmental Support Services (**ESS**) for a broader group of people. This includes those outlined above, people with disabilities associated with ageing, people first referred over the age of 65 and people aged under 65 with disabling chronic health conditions.

A person's diagnosis is a factor in determining eligibility for disability support services funded by DSS but is not the main determinant. It provides a guide as to whether a person is:

- likely to have, or likely to develop (in the case of young children), a physical, sensory, and / or intellectual disability and also whether the person is likely to have ongoing support needs mainly due to this disability
- likely to have primarily personal health needs that could be significantly ameliorated by treatment and / or that are likely to require ongoing clinical intervention.

### **Applying the definitions of physical, sensory, and intellectual disability**

The DSS definition of tāngata whaikaha who receive disability support funding is informed by the disability type definitions in "Support for Independence for People with Disabilities: A New Deal"<sup>14</sup> (refer Appendix 1 for a list of these definitions).

The sub-groups within the broader group of tāngata whaikaha accessing DSS individualised services are listed below. Impairments under each sub-group are accompanied by examples of conditions that may result in these types of impairments, but this is not intended to be a diagnostic 'in' and 'out' list.

#### *Physical disability*

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<sup>14</sup> Minister of Social Welfare and Minister of Health. *Support for Independence for People with Disabilities: A New Deal*. 1992. Wellington: Parliament Buildings.



People who have physical disabilities accessing DSS support services includes people with impaired limb function affecting independence in activities of daily living and / or mobility<sup>15</sup>.

Physical disability may be due to (but is not limited to):

- partial / total absence or loss of limbs (e.g., at birth or following amputation because of diabetes)
- structural impairments of limbs (e.g., achondroplasia)
- paralysis (e.g., hemiplegia following a stroke or brain tumour; paraplegia due to spina bifida; tetraplegia due to debulking of a spinal tumour)
- reduced muscle strength (e.g., following Guillain-Barre)
- ataxia<sup>16</sup> (e.g., with cerebral palsy or multiple sclerosis)
- muscle wasting (e.g., with muscular dystrophy or motor neurone disease)
- muscle tone abnormalities (e.g., due to acquired brain injury not covered by ACC)
- limited range of movement (e.g., juvenile rheumatoid arthritis, osteoarthritis).

Some impairments arising from significant skeletal malformations (e.g., severe scoliosis) may also meet the physical disability eligibility criteria, depending on the nature of the resulting impairment.

### *Sensory disability*

People who have sensory disabilities accessing DSS support services includes people with the following types of long-term sensory impairments that are generally not responsive to treatment and affect independence in activities of daily living and / or mobility<sup>17</sup>:

- blind
- deaf
- deafblind
- significant visual impairment

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<sup>15</sup> This group includes people with chronic medical conditions who, following active treatment and rehabilitation, are assessed as having a long-term physical disability and an ongoing support need **where physical disability** (as opposed to physical incapacity) **is the primary reason for support**.

<sup>16</sup> Ataxia is a lack of muscle co-ordination during voluntary movement, such as walking or picking up objects, generally due to disorders in the brain or spinal cord.

<sup>17</sup> This group includes people with chronic medical conditions who, following active treatment are assessed as having a long-term sensory disability and an ongoing support need **where sensory disability is the primary reason for support** (e.g. blind due to diabetes).

- significant hearing impairment
- significant other sensory loss (e.g., no taste or touch — rare)<sup>18</sup>.

### *Intellectual disability*

People with learning or intellectual disabilities accessing DSS support includes people with intellectual disability present at birth or generally acquired in the development years (before age 18) (e.g., due to Angelman's syndrome, microcephaly, or meningitis).

A NASC may request a specialist assessment to confirm a person has an intellectual disability. This may include a cognitive assessment (generally, an IQ test score of up to 70 indicates a limitation in intellectual functioning) and standardised assessment of adaptive functioning in the areas of conceptual skills, social skills, and practical skills.

Eligibility for DSS funded Intellectual Disability Compulsory Care and Rehabilitation services is legislatively mandated (Section 7 of the Intellectual Disability [Compulsory Care & Rehabilitation] Act 2003 refers).

Where a person has been assessed as eligible for disability support services based on a physical or sensory disability and the person has a co-existing significant intellectual impairment that was acquired at age 18 or older and is not covered by another funder (e.g., ACC), DSS may fund the full package of support.

### **Other eligible groups**

There are certain other groups that DSS funds support services for whose impairments do not strictly meet the DSS definition of physical, sensory, or intellectual disability. Their inclusion generally reflects long-standing practice.

### *Disability in young children where presence of a physical, sensory and / or intellectual disability is not yet confirmed*

DSS funds disability support services for children who are medically stable and have significantly delayed physical, intellectual, and / or sensory development (often global developmental delay) for whom there are indicators of likely long-term physical, sensory, and / or intellectual disabilities and where clinical or rehabilitative intervention is not expected to significantly reduce the need for long-term support. Eligibility is on an interim basis until a long-term disability (usually an intellectual disability) with associated ongoing support needs is confirmed (generally by age 7).

If the presence of a long-term disability and ongoing support need is not confirmed, the NASC Service Coordinator facilitates the gradual withdrawal of

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<sup>18</sup> Note, sensory impairment does not include hypersensitivity or perceptual impairments such as auditory processing disorder.

DSS funded supports. Health NZ specialist clinical and allied health services may continue to be available to these children.

*Disability associated with acquired brain injury and certain neurological conditions*

DSS has funded disability support services for some people who have acquired brain injuries and certain neurological conditions that do not result in a physical or sensory disability or an intellectual disability that meets the intellectual disability criteria described above<sup>19</sup>.

This included some people who, after treatment and rehabilitation, have long-term significant cognitive impairment (e.g., due to multiple sclerosis, a stroke, or a benign brain tumour). Clinical reports were generally required to support the referral to NASC. Eligibility decisions took into consideration the age of the person, whether the person has any significant co-existing medical conditions and the nature of the person's support need.

DSS **does not** fund disability support services for people who require support:

- due to cognitive impairment arising from a mental illness or addiction or due to the consequences of treatment for these conditions (e.g., people with Korsakoff's psychosis or other substance induced brain damage)
- solely due to behavioural problems.

*Autism Spectrum Disorder (ASD)*

Effective April 2014 the Ministry of Health's DSS and Mental Health groups jointly agreed a national position with respect to people diagnosed with ASD<sup>20</sup>. This enabled people with ASD to be considered for DSS regardless of whether they also have a co-existing physical, intellectual, or sensory disability.

The clarification was made to:

- address inconsistent access and practice across the country
- recognise there are still service gaps requiring service development
- commit to a joined-up solution where organisations and funders work together in finding pragmatic and sustainable solutions for this group of people.

## **Needs assessment and service co-ordination process**

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<sup>19</sup> When LTS-CHC devolved to DHBs in 2011 clarification was made that people with cognitive impairment without a physical, sensory, or intellectual disability would remain part of LTS-CHC client group. Funding was devolved accordingly.

<sup>20</sup> From its establishment on 1 July 2022, Ministry of Disabled People – Whaikaha (**MoDP**) continued with this national position. From 16 September 2024, DSS and related funding and service delivery responsibilities were transferred from MoDP to the new DSS business unit within MSD.

Any person assessed by a NASC as likely to meet the DSS eligibility criteria is entitled to have a needs assessment to identify disability support needs and assessed goals. This does not confer an automatic entitlement to services as the provision of services is prioritised based on the person's level of assessed need related to their disability.

The needs assessment includes assessing, wherever possible, what is primarily driving the person's support need. Support needs that are not primarily attributable to an ongoing physical, sensory, and / or intellectual disability or an impairment included in sections 1 to 4 above (denotes disability support services eligibility) are not the funding responsibility of DSS<sup>21</sup>. Where a DSS eligible disability is contributing to broader support needs, DSS will negotiate joint funding or joint service package arrangements with the relevant other funder.

When a person presents for assessment for disability support services between the ages of 50 and 65, the DSS NASC also screens the referral to determine whether the person is likely to meet the 'close in interest' criteria<sup>22</sup>. If screening indicates that the person is likely to meet these criteria, the NASC forwards the referral on to a Health NZ needs assessment service.

If the needs assessment confirms that the person has disability support needs, a service co-ordination process follows to determine:

- what natural supports the person has to meet these needs<sup>23</sup>
- which needs can be fulfilled within the range of services DSS funds within its capped budget
- where other avenues of support are indicated (with a view to referral to appropriate services).

For people assessed as eligible for disability support services funded by DSS, the services available to meet their support needs are services that already exist within the DSS service framework<sup>24</sup>.

### **DSS disability support services funding exclusions**

DSS does not fund support services for people with conditions or situations covered by other funders including:

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<sup>21</sup> In practice, some funding for supports needed due to co-existing conditions does occur.

<sup>22</sup> Refer to the 'MSD DSS Operational Policy: Close in Interest'.

<sup>23</sup> In the case of young children, this includes taking account of the level of support a parent would normally be expected to provide for a child of that age.

<sup>24</sup> This is the current arrangement, however the Demonstration Projects to implement the New Model for Disability Support and Enabling Good Lives includes expanding the range of services that people under Individualised type funding arrangements can purchase with their allocated support funding, through contracted and non-contracted providers.

- support to address short-term needs (i.e., less than six months' duration), for example following surgery or medical events<sup>25</sup> (Health NZ's Personal Health)
- support for people who first present for assessment for long-term supports at age 65 or over (Health NZ's Health of Older People - CAB Min (03) 5/5 refers)
- support for people who first present for assessment for long-term supports between ages 50 and 65 who are clinically assessed by a Health NZ clinician or needs assessor as being 'close in interest' to older people<sup>26</sup> (Health NZ's Health of Older People - CAB Min (03) 5/5 refers). Refer to the 'MSD DSS Operational Policy: Close in Interest'.
- aged residential care for disabled people funded by DSS who have been reassessed by a Health NZ needs assessor as requiring this service (Health NZ's Health of Older People - CAB Min (03) 5/5 refers)
- support for people who first present for assessment for long-term supports before the age of 65 whose support need is due to impairments that do not meet the DSS operational definition of physical, sensory, or intellectual disability. This includes people who will be referred to Health NZ's Long Term Supports – Chronic Health Conditions services.
- support for 'medically fragile children'. These are children with high health needs and/or multiple impairments whose health status has not yet stabilised and for whom a physical, sensory and/or intellectual disability with associated ongoing support needs has not been identified (Health NZ's Personal Health / Long-term Supports – Chronic Health Conditions [LTS-CHC], Primary Care)
- support for needs arising primarily from physical incapacity (e.g., shortness of breath, fatigue, or pain) due to a chronic health condition (Health NZ's LTS-CHC / Personal Health, Primary Care)
- support for additional care needs arising from a condition in the palliative stage<sup>27</sup> (Health NZ's Palliative Care)
- support for needs arising from a mental illness and / or addiction<sup>28</sup> including physical, sensory, and cognitive impairments attributable to this

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<sup>25</sup> This includes 'topping up' existing DSS support packages for disabled people supported by DSS funding in these situations.

<sup>26</sup> People with long-term conditions more commonly experienced by older people and requiring integrated health and disability support services.

<sup>27</sup> This includes specialist palliative care services for people receiving DSS disability support services.

<sup>28</sup> Responsibility for planning and funding disability support services for people with psychiatric disabilities was devolved to DHBs in 2001 (CAB Min (01) 12/12 refers). All residual contracts and funding were devolved in 2003 (CAB Min (03) 23/8 refers).

underlying condition, for example: tardive dyskinesia due to long-term use of psychotropic medication, cognitive impairment due to alcohol or other substance abuse, impaired mobility due to alcohol related peripheral neuropathy or functional difficulties due to conversion disorder (Health NZ's Mental Health and Addiction / LTS-CHC, Primary Care)<sup>29</sup>

- support services needed primarily because of dementia or substance abuse (Health NZ's Health of Older People / Mental Health of Older People / LTS-CHC, Primary Care)
- support services needed primarily because of behavioural problems (e.g., associated with Foetal Alcohol Syndrome or substance abuse) except where the person has a co-existing disability that meets DSS eligibility criteria<sup>30</sup> (some services are funded by other government agencies, in other situations this is a funding gap)
- support due to an injury that meets ACC's cover and entitlement criteria under the Accident Compensation Act 2001<sup>31</sup>
- support for situations covered by other central government agencies such as the Ministry of Education and MSD (beyond services provided by the DSS business unit)<sup>32</sup>.
- support needs solely due to social/environmental factors (e.g., housing or where parents need support for their own health needs). [Some services are funded by other government agencies, in other situations this is a funding gap.]

## Cross-funder relationships

### Shared arrangements for people with DSS eligible disabilities and other conditions

Joint funding or shared service arrangements may apply where a person assessed as needing formal support:

- meets DSS eligibility and access criteria, **and** has a personal health condition, chronic health condition, condition in the palliative stage, mental illness and / or addiction, and / or injury.

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<sup>29</sup> People who have a mental illness and/or addiction and a co-existing physical, sensory or intellectual disability that meets DSS eligibility criteria may receive both Health NZ and DSS funded supports.

<sup>30</sup> Where a person has behavioural issues due to an acquired brain injury or certain degenerative neurological conditions (e.g., Huntington's disease) secondary to a co-existing physical, sensory, or intellectual disability, DSS may fund the full support package.

<sup>31</sup> Refer to footnote 13.

<sup>32</sup> Some people will receive supports from both DSS and another agency or agencies.

Where a person has support needs arising from both a DSS eligible disability type and a co-existing condition or situation for which another funder (e.g., Health NZ, ACC, or Ministry of Education) has support funding responsibility, DSS will negotiate joint funding or shared service arrangements with the relevant other funder. DSS contributes to the person's support package by funding the disability support services required because of the DSS eligible disability.

In complex situations where the cause of impairment is unclear (e.g., injury vs acquired) or a person has multiple impairments or causes of impairments, DSS works with other funders to determine a pragmatic joint funding or shared services arrangement to support prompt access to essential supports. Further work is needed across funders to agree consistent and efficient pathways for resolving funding responsibility in these situations.

### **Resolving funding responsibility between DSS and Health NZ**

Where there is disagreement between funders over whether a person's support needs are the funding responsibility of DSS or Health NZ, it is important that the interests of the person needing support are protected in the first instance.

The following resolution procedures apply:

- any disagreement about access to DSS or Health NZ funded services will be resolved in the first instance by discussion between the relevant needs assessment services
- where resolution cannot be achieved through discussion between DSS and Health NZ needs assessment services, the first level of escalation will be to the operational management within DSS.

### **Transferring funding responsibility**

In respect of moving people receiving disability support between DSS and Health NZ Health of Older People funding (CAB (03) M 23/8 refers), disabled people receiving disability support from DSS can move to receive support from Health NZ, but Health NZ-supported people cannot move to being supported by DSS<sup>33</sup>. A disabled person receiving support funded by DSS will move to be supported by Health NZ funding only if they are reassessed as requiring aged residential care.

### **Transfers between DSS and Health NZ Long-term Support Chronic Health Conditions funding**

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<sup>33</sup> Note that even if the person had previously been supported by DSS funding, having moved to being funded by Health NZ they cannot return to DSS for funding. All movements are one way, from DSS to Health NZ, unless both funders agree that the funding associated with that person has been incorrectly devolved or incorrectly assessed.



People supported by Health NZ Long-term Support Chronic Health Conditions (LTS-CHC) can move to be supported by DSS funding (or to shared funding arrangements) if they acquire a disability that meets DSS eligibility and access criteria, and this disability is now the main reason why the person needs ongoing support.

## Further information

### Disability support services that do not require a NASC assessment

While most disability support services are accessed through a NASC process, some services can be accessed on self-referral, GP referral or referral by a qualified person.

Services that can be accessed on self and/or GP referral include:

- Disability Information and Advisory Services (**DIAS**)
- some services supporting people with hearing or visual impairments.

Services generally accessed through referral by a qualified person (often a health professional) include:

- Child Development Services (**CDS**)
- Assessment Treatment and Rehabilitation (**AT&R**) Services
- most Environmental Support Services.

#### *Disability Information and Advisory Services (DIAS)*

DIAS provide information for disabled people and other members of the community on how to find support and advocacy groups, NASC services or community support organisations, specific information related to particular disabilities, and other topics related to disability.

#### *Child Development Services (CDS)*

CDS are multidisciplinary community-based services that provide specialist assessment, intervention, and management services for young children (mostly pre-schoolers) who have disabilities or who are not achieving developmental milestones. DSS funds the allied health component of these services. CDS work with other agencies to support children to achieve their potential.

#### *Assessment, Treatment, and Rehabilitation Services (AT&R)*

Health NZ-funded AT&R services are Health NZ District-provided multidisciplinary services delivered in a range of settings for disabled people under the age of 65. They include specialised and clinical assessment, treatment, and rehabilitation to enable people to participate in daily activities and fulfil valued roles in their home and community.

#### *Environmental Support Services (ESS)*



Environmental Support Services are a range of services and supports funded by DSS that are available to a broader group than disability support services accessed via DSS NASCs. They include:

- Equipment and Modifications Services (**EMS**) — such as equipment, housing modifications and vehicle purchase and modifications)
- supports and services for people with hearing loss (e.g., hearing aids, hearing aid subsidies, cochlear implants and services, New Zealand Sign Language (**NZSL**) interpreter services, and hearing therapy)
- supports for people with vision loss (such as spectacle subsidies, and services for blind and deafblind people)
- some specialised assessment services (such as wheelchairs, seating and postural management and communication assistive technology) and assessor training.

ESS are funded through DSS for:

- people with physical, sensory, and intellectual disabilities
- people with disabilities associated with ageing
- people aged under 65 with disabling chronic health conditions.

People access EMS and hearing aid and spectacle subsidies via a specialised assessment with a Health NZ assessor or a private assessor (the person may pay for services such as audiology) who is a suitably skilled or qualified person (e.g., an allied health professional or an audiologist who is an approved or credentialed EMS Assessor as described in the DSS Accreditation Framework).

Access to services is prioritised so that people with the most urgent needs receive services first. A prioritisation tool for EMS has been developed which prioritises access to resources based on a person's ability to benefit from the service and other relevant factors.

## **Health and disability services funded in New Zealand**

The 'Health and Disability Services Eligibility Direction 2011' (the Direction) sets out the groups of people eligible for publicly funded health and disability services in New Zealand. This direction was made by the Minister of Health under section 32 of the New Zealand Public Health and Disability Services Act 2000. The direction became effective on 16 April 2011, and applies from that date forward. Part B1 states that a person is eligible under the Act if the person is in New Zealand when the services are received.

A person must meet one of the criteria in the Eligibility Direction to be considered for these publicly funded services. If the person is not eligible, they are liable to be charged for the full costs of any medical treatment or disability support service received.

## Useful documents

- [Guide to Eligibility for Publicly Funded Services | Health NZ](#)
- [Health and Disability Services Eligibility Direction 2011](#)
- MSD DSS Operational Policy: Close in Interest

# Appendix 1: Definitions

## **Government's definition of 'person with a disability' for the purpose of accessing disability support services [CAB (94) M 3/5 (1a)]**

A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these), which is likely to continue for a minimum of six months and result in the reduction of independent function to the extent that ongoing support is required.

Where a person has a disability which is the result of a personal injury by accident which occurred on or after 1 April 1974, it should be determined whether they are eligible for cover under the Accident Rehabilitation and Compensation Act.

Where a person's level of independent function is reduced by a condition which requires ongoing supervision from a health professional (e.g. in the case of renal dialysis), that person is considered to have a personal health need rather than a disability. Where a person has both a disability and a personal health need, the services provided to address those needs are disability support services and personal health services respectively.

After this definition being agreed by Cabinet, Cabinet decided to transfer responsibility for some disability groups to DHBs. Funding responsibility for disability support services for people with psychiatric disability transferred to DHBs in 2001 and for people with age-related disability in 2003<sup>34</sup>. The latter group included:

- people who first present for assessment for disability support services at age 65 and over, and
- people aged between 50 and 65 who are clinically assessed as 'close in interest' to older people (having poorer health and disability status than the general population and conditions/disabilities normally acquired at age 65 or over).

## **Definitions in "Support for Independence for People with Disabilities: A New Deal"**

[Minister of Social Welfare and Minister of Health. 1992. *Support for Independence for People with Disabilities: A New Deal*. Wellington: Parliament Buildings]

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<sup>34</sup> Note, this devolution also included residual MoH funded long-term support services for people with personal health conditions, mental illnesses, and palliative care needs.

- “Physical disability - reduced physical capacity (for example, through loss or impaired use of limbs)
- Sensory disability - impairment of the senses (mostly sight and hearing)
- Intellectual disability - permanently impaired learning ability (usually from birth) which prevents or inhibits people from developing the range of physical and social skills usually found in a person of that age
- Psychiatric disability - disability arising from continuous or intermittent disorders related to thinking, feeling, volition, or behaviour (for example, schizophrenia, severe chronic depression, or long-term addiction to alcohol and drugs)
- Age-related disability - physical, intellectual, or psychiatric conditions related to the onset of old age. This includes conditions that can affect younger people, such as Alzheimer’s disease or stroke, but which are more often found amongst older people”.

## Glossary: Terms and definitions

Term	Description
<b>ASD</b>	Autism Spectrum Disorder
<b>AT&amp;R</b>	Assessment, Treatment and Rehabilitation services
<b>CDS</b>	Child Development Services
<b>DIAS</b>	Disability Information and Advisory Services
<b>DSS</b>	Disability Support Services (business unit)
<b>ESS</b>	Environmental Support Services
<b>Health NZ</b>	Health New Zealand   Te Whatu Ora
<b>LTS-CHC</b>	Long Term Support needs resulting from Chronic Health Conditions
<b>MoH</b>	Ministry of Health
<b>MSD</b>	Ministry of Social Development
<b>NASC</b>	Needs Assessment and Service Co-ordination
<b>NZSL</b>	New Zealand Sign Language
<b>RHA</b>	Regional Health Authority
<b>Tāngata whaikaha</b>	Disabled people and tāngata whaikaha Māori
<b>Whaikaha</b>	Whaikaha — Ministry of Disabled People



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# **Operational Guideline**

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**Operational Guideline for the Assessment of Intellectual  
Disability to Access Disability Support Services Contracted for People  
with Intellectual Disability in New Zealand 2021**

**Prepared by Disability Support Services  
ID Eligibility Version TR 2021**

## Introduction and Purpose

The Ministry of Health (Ministry) funds a range of Disability Support Services. These are available to eligible New Zealanders who have physical, intellectual or sensory disabilities that are likely to continue for at least six months and which limit their ability to function independently.

Needs Assessment and Service Coordination Organisations (NASCs) coordinate several services available to people predominantly under 65 with a variety of disabilities. These services have criteria for eligibility.

This document has been developed as a guide for both Needs Assessment Service Coordination Organisations (NASCs) and psychologists conducting assessments for intellectual disability. This document details the correct and necessary processes required to establish eligibility to receive services funded by Ministry of Health Disability Support Services (DSS) for people with intellectual disability. Appendix 1 provides information about NASCs in New Zealand.

The Ministry has consulted with and involved clinicians in the development of this document and used both national and international standards as outlined in the consideration section below. In addition, Māori and Pacific cultural experts have been consulted to ensure that the guidelines reflect both good cultural practice and obligations under Te Tiriti O Waitangi. Use of the guidelines must reflect a level of cultural competence to meet both aspirations for Māori and Pacific and ensure that equity is addressed for Māori, Pacific and other vulnerable populations.

Clinically, these guidelines have been developed with consideration to:

- American Association of Intellectual and Developmental Disabilities: Intellectual Disability: Definition, Classification, and Systems of Supports.
- American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (2022).
- Pearson Clinical Australia and New Zealand.
- Ministry of Health: Service Specifications for Behaviour Support Services (2014).
- Ministry of Health: Service Specification for Needs Assessment and Service coordination Organisation, (2005, reviewed September 2007).
- New Zealand Council for Educational Research: Psychological Test Services ([www.nzcer.org.nz/pts](http://www.nzcer.org.nz/pts)).
- New Zealand Psychological Society, New Zealand College of Clinical Psychologists, New Zealand Psychologists' Registration Board: Code of Ethics for Psychologists Working in Aotearoa / New Zealand (2002).
- World Health Organization: International Classification of Diseases, 11th Edition (ICD-11) (2019).

**This document should be read in conjunction with Ministry of Health Disability Support Services Operational Policies.**

## Overview Eligibility Statement for Resource Allocation

This guideline provides information and advice to assist NASCs and Registered Psychologists in determining whether a person is eligible to access funded disability services based on the criteria of intellectual disability. This guideline should provide clear eligibility information to all those involved during this process so that NASCs can contribute to service coordination decisions made for access to funded Disability Support Services.

The Ministry requires NASCs to determine a potential client's eligibility to access funded disability support services. It is required that eligibility is confirmed before services are provided. The NASC facilitates assessments from appropriately qualified health professionals to determine if a person meets diagnostic criteria for an intellectual disability. The NASC will then establish if they have associated disability support needs.

There are services that have been specifically developed and are funded for people with an intellectual disability. These assessments establish whether an individual is eligible to access these support services. These are publicly funded services that form part of a set of limited resources for people with disabilities available from across government services.

The Ministry is responsible for allocating resources that are suitable to meet identified disability related needs. The NASC is responsible for determining the need for person centred supports from within an available framework. The NASC does not focus on services delivered from agencies outside of the service framework. The needs assessment process assists in making decisions about what services from within the DSS framework are appropriate to meet the identified need.

It is important that people are given the least intrusive and restrictive options to have their support needs met. When accessing services, it is not always possible to meet the diverse needs posed by all individuals. Therefore, service provision can restrict people's freedoms and choices. For this reason, it is important to consider the impact of services when making recommendations.

When making a decision about eligibility, it is important to know the eligibility criteria for your target population. It is also important to know the services funded and provided by other government and NGO organisations. When you have a clear understanding of service boundaries you are better able to make decisions and give advice on eligibility.



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# What is Intellectual Disability?

## ***Terminology:***

Internationally, several terms have been used to describe people who have significant impairments in intellectual and adaptive functioning throughout their lives. These have included mental retardation, mental handicap and learning disability<sup>1</sup>. The World Health Organisation refers to “Disorders of Intellectual Development”<sup>2</sup> and the American Psychiatric Association refer to intellectual disability as “Intellectual Developmental Disorder (Intellectual Disability)”<sup>3</sup>. In New Zealand, and now in most of the world, the most acceptable term at the time of this guideline is “intellectual disability”, which is also consistent with New Zealand legislation<sup>4</sup>.

People who have an intellectual disability may have problems in daily living, poor memory, and learning difficulties throughout their lives. This population is often vulnerable and can exhibit poor coping skills, particularly in times of crisis. They may also be dependent on others for support depending on the severity of their difficulties.

There are no specific physical features associated with intellectual disability, although there are genetic syndromes where intellectual disability can be one of the clinical features of the syndrome, for example Down Syndrome.

There is also a common error when people assume that certain syndromes, such as Foetal Alcohol Spectrum Disorder, are always associated with intellectual disability. It is possible for people with syndromes and other presentations, such as Autism, not to have a concurrent intellectual disability.

There should be no assumption made of a direct relationship between a diagnosis and eligibility for support services. Access to disability services is based on the presence of a permanent impairment meeting the criteria for an intellectual disability and evidence of unmet disability support needs that could be reasonably met within the disability service framework.

## ***Causes (Etiology):***

An individual's intellectual ability is the result of the interaction between their genetic endowment and their developmental environment. While an individual's genetic endowment will determine their potential optimal intellectual ability, development of this is dependent on exposure to an appropriately facilitating environment. Both biological and psychosocial aspects need to be met from conception right through to adulthood to maximise ability.

The genetic determinants can include specific syndromes where intellectual disability is only one manifestation of the syndrome. However, in most cases of intellectual disability no specific genetic syndrome can be identified. Most individuals will have developed within an appropriately facilitating environment and all that may be concluded is that like other areas of development, such as height, they are individuals whose IQ scores are in the lower range of the population's IQ distribution, and they have reached their full intellectual potential. There are, however, cases where there will have been some impediment to the individual reaching their full potential. Biological factors can have an impact in utero, during birth and postnatally, and can include a wide variety of etiologies, including physical trauma, exposure to substances or toxins, and infections. The effects can range from mild to being extremely severe. Psychological factors, including neglect, abuse and disruption to education, can likewise limit the final intellectual development of the individual.

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<sup>1</sup> In this context intellectual disability means an intellectual impairment and deficits more severe and across a number of functional areas as opposed to an impairment which means a limitation that is discreet.

<sup>2</sup> World Health Organization (2019). International Statistical Classification of Diseases and Related Health Problems (11th ed.). <https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2fcd%2fentity%2f605267007>

<sup>3</sup> American Psychiatric Society (2022) Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5TR) (2022), Washington DC: Author. <https://ebooks.appi.org/epubreader/diagnostic-statistical-manual-mental-disorders-fifth-edition-text-revision-dsm5tr>

<sup>4</sup> Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

## Diagnostic Criteria:

In accordance with major international texts<sup>5</sup> and New Zealand legislation, the diagnosis of an intellectual disability can only be made if the criteria discussed below are permanent. There are three mandatory criteria for the diagnosis of an intellectual disability. The criteria are significantly sub-average intellectual functioning, deficits in current adaptive functioning, and that the individual's impaired functioning was apparent before the age of 18. These criteria are expanded further below.

<b>1. Cognitive Functioning</b>	<p>In the context of the definition of “intellectual disability”, an individual is seen as having “significantly sub-average intellectual functioning”. This equates to at least two standard deviations lower than the mean (average) on an individually administered IQ test, most of which would result in an IQ of approximately 70 or below. The level of disability may be further classified as Profound, Severe, Moderate or Mild.</p>
<b>2. Adaptive Behaviour</b>	<p>Deficits or impairments in current adaptive functioning in at least two of the following areas: communication, self-care, home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.</p>
<b>3. Developmental History</b>	<p>Most people who are diagnosed with an intellectual disability have evidence of this from birth or infancy. There are, however, some people whose intellectual disability is not evident until later in their development. There is a threshold in the diagnosis in that the onset is before 18 years of age. This does not mean that an assessment before the age of 18 is required, but there should be supportive information that significant deficits were evident before 18.</p> <p>Meeting this criterion is essential for the diagnosis of an intellectual disability. The impairments in cognitive and adaptive functioning must be permanent and evident during the person’s developmental period.</p> <p>A person with significantly impaired cognitive functioning as a result of dementia, adult head injury, long term and severe mental health disorder, or substance abuse, but who was</p>

<sup>5</sup> Please see appendix 2 Operational Guidance for the Assessment of Intellectual Disability to Access Disability Support Services, Ministry of Health 2014.

	functionally normal before 18, does not have an intellectual disability and is excluded from such a diagnosis.
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## ***Processes:***

**Quality of Information** – When assessing whether a person has an intellectual disability, it is important to have reliable evidence from credible sources. The reliability of the source needs to be considered based on factors that may include whether there is any specific motivation to provide biased information; whether the person being assessed is putting in their best effort at psychometric assessment; whether the environment is appropriate to gather reliable and valid information.

**Clinical Interview** – Psychologists should reflect critically on their ability to establish rapport with the participant in testing. A participant's full effort is required in neuropsychological testing for valid data to be collected. Tests of effort/performance validity should always be used to objectively establish test effort. Psychologists are not always able to detect poor effort that could be the result of low motivation, intoxication, mental illness and co-morbid presentations, including attention deficit hyperactivity disorder (ADHD), personality disorder, undue anxiety, fatigue, illness, or contention about diagnosis. Particularly in forensic contexts, participants can be coached to under-perform to access more lenient disposition options or gain access to services they might not be entitled to.

**Data Gathering** – Collateral information required for a complete assessment of intellectual disability is likely to include an interview with the person, immediate family/whānau members and/or carers. This may also include other professionals involved, such as nurses, doctors, psychologists, case managers, psychiatrists, social workers, ministers, and teachers. Where possible this should also include an overview of supporting documentation and observation of the client.

It is important for any assessor to be aware that the results obtained from standardised assessment instruments are affected by a variety of variables including, but not limited to, ethnicity, first language, rapport, socio-economic status, sensory impairments, communication impairments, test anxiety, mental illness, substance use, personality, and social and cultural influences. Effective gathering of pertinent information at this point assists with the overall interpretation of these tests and the diagnosis reached at the completion of the assessment. This is particularly important in young people where standardised test scores can be low due to neglect and disrupted access to education, but wider assessment reveals adaptations that would not be expected in someone with an intellectual disability.

**Analysis of Data and Information** – Caution is required when making the diagnosis of an intellectual disability. While for many individuals, the diagnosis can be for the best of reasons, such as providing the person with social supports, it must be kept in mind that the diagnosis may have a long-term negative impact and may also be challenged in Court. The psychologist's role is to make an objective, transparent assessment with conclusions based on the best supported hypothesis and clinical consideration of alternatives (i.e., that the person does not have an intellectual disability).

**Clients Unable to be Tested** – There are generally two types of people who are unable to be psychometrically assessed. The first group are those who are so impaired, and have been over their lifespan, that their disability is evident without the use of psychometric tests. The DSM-5TR makes specific provision in exceptional circumstances for psychologists to make a diagnosis of unspecified intellectual disability when assessment of individuals over five years of age is rendered difficult or impossible because of associated physical, sensory, motor, behavioural, or mental health disorders. The second group are those who actively choose not to apply full effort in psychometric assessment, preventing collection of valid data.

In the absence of reliable information or where there is doubt about the validity of data, a decision may still be required. When this occurs, supervision should be sought by the psychologist, and consideration given to the issues raised in the Scientific Review of Mental Health Practice. Conclusions based on any situation when a person has been unable to be validly psychometrically assessed must be made with appropriate cautions and these need to be noted in any related report.

## ***Borderline Intellectual Functioning:***

A terminology problem often encountered in the area of assessment for intellectual disability is the use of the term 'borderline' intelligence. People mistakenly use this term believing that the word 'borderline' may mean consideration for inclusion with the group of people diagnosed as having an intellectual

disability. This is not the case and there is no such classification code for 'borderline intellectual disability'. It is recommended that the term 'very low intellectual functioning' is used instead of 'borderline intellectual functioning' in order to reduce confusion about this.

Differentiating mild intellectual disability from very low intellectual functioning requires careful consideration of all available information including the standard error of measurement. People who are reported as having very low intellectual functioning are not eligible for intellectual disability services.

#### Notes for NASC

**IQ Cut Off:** Diagnostic criteria allow for consideration to be given to standard error of measurement for the standardised tests used. This variable is used because IQ tests are not sensitive enough to yield accurate, specific IQ scores. This allows clinicians the ability to statistically evaluate performances outside the score range (i.e., over 70). These ranges are provided within the test manual. For this reason, it is possible for a person to be diagnosed with an intellectual disability when their IQ score is just above 70 IQ points. A NASC should not adopt and apply its own individual IQ cut off scores for entry to services, nor should it provide their own definitions of adaptive functioning deficits. Be aware that increasing acceptance to include those with IQ scores in the very low range but outside the set criteria for an intellectual disability, will include those outside of the range services have been developed for, will impact delivery frameworks and funding thresholds due to an increase in the number of people accessing services.

*In January 2022, the New Zealand population was around 4.9 million. 2% of the population, have a FSIQ of 70 or below. This means 98,000 people would be expected to meet the first diagnostic criterion of significantly sub-average intelligence. 4% of the population has a FSIQ of 73. Universally accepting this higher threshold would mean the number of people potentially eligible for services would double. This would lead to disability services being inundated with demands that they would not be able to meet.*

The important issue for the NASC is the concluding diagnostic decision. There should be no expectation on the psychologist to provide their raw data as to do so may contravene their Code of Ethics and good clinical practice.

Mild intellectual disability is more prevalent than moderate, severe or profound intellectual disabilities. Approximately 85% of people with an intellectual disability will be classified as having a mild intellectual disability. At this time classificatory labels are defined by bands of IQ scores (based on IQ tests) or adaptive functioning needs (as in the DSM-5TR). The actual classification label may have a limited relationship to a person's support needs.

Ministry of Health contracted services are purchased on behalf of people with an intellectual disability. Diagnostic guidelines give very specific instructions about how intellectual disability is to be diagnosed. Therefore, it is the presence of the intellectual disability that establishes eligibility (along with established support needs) to access these services, not the guidelines from individual NASC organisations.

If a report states that someone is unable to be tested, you should discuss this with the assessor in the first instance and, if necessary, agree to gain a second opinion, particularly if the information appears ambiguous or where clinical judgement was the only element used in the assessment. If the psychologist who completed the first assessment questions this process, inform them that this is a standard requirement in such cases. It may be courteous to ask if they are able to assist in identifying a suitable person to provide the second opinion.

## Notes for Psychologists

An ongoing issue in eligibility testing is determining the maximum IQ score that would still allow a person to meet the criterion of significantly subaverage intelligence is support of a diagnosis of intellectual disability.

Intelligence testing is an imperfect proxy to general intelligence and a statistical boundary (two standard deviations below the mean) that defines the presence of disability, is somewhat arbitrary. Despite that, by virtue of being a reasonably objective measure, the FSIQ tends to play a central role in the diagnosis of intellectual disability.

IQ scores are often reported in ranges, typically four to five points either side of the FSIQ, on the basis that IQ tests are subject to too many variables to accurately detect IQ to a single point. Assuming we are using a 95% confidence interval, we are essentially saying that there is a 95% probability that the individual's IQ falls somewhere in that range (assuming they applied reasonable effort).

When someone yields a score in the range 62-70 (providing there is evidence of good effort) we can be reasonably confident they meet the IQ criterion required for intellectual disability. Equally, if someone scores in the range 71-79, we can be confident they fall outside the criteria. Determining eligibility becomes more complicated when the reported range spans the typical cut-off of FSIQ 70.

The first point to consider is a technical one. Whilst psychologists often report a range of scores based on a 95% confidence interval, it is most likely the individual's true score lies towards the centre of that range and increasingly less likely it lies at the extremes. Therefore, whilst it is possible to suggest that because someone yielded an FSIQ of 74, their true IQ could be 70 (and therefore eligible) it is unlikely and therefore somewhat tenuous.

It is suggested that when FSIQ scores fall within the range 68-74, there is an emphasis on careful, objective consideration of the best supported hypothesis, based on an assessment of the complete clinical landscape - rather than test scores alone. Information from additional cognitive tests or multiple IQ tests may help to provide more information to help understand a person's intellectual profile when there is limited clarity from one comprehensive assessment measure. IQ scores in this range also necessitate a greater interrogation of test effort, confounding variables (e.g., limited access to education), and both quantitative and qualitative assessments of adaptive functioning.

The diagnosis of intellectual disability can bring individuals and their families welcome support. This can unconsciously motivate psychologists to suggest people are eligible when more objective weighing of the evidence could result in a different conclusion. It should also be noted that, in addition to issues of stigma, a diagnosis of intellectual disability can have a significant influence on outcomes in the criminal justice system, with 'generous' diagnoses of intellectual disability contributing to erroneous findings of 'unfit to stand trial' and placement in inappropriate services. Finally, the nature of a normal distribution means that raising the IQ threshold of intellectual disability has an exponential impact on the number of people eligible for disability support services. Raising the threshold by four points, to FSIQ 74, would double the number of people eligible, overwhelming resources and directing people towards services that are often inappropriate for people with general intelligence in the very (but not extremely) low range.

Where there are significant differences in the composites comprising the FSIQ (i.e., greater than 23 points) the FSIQ should still be reported for the purposes of eligibility as it is the greatest predictor of actual intelligence. There is a misnomer that the FSIQ cannot be reported in this situation. Instead, the psychologist should note that whilst the FSIQ is provided for the purposes of eligibility, it is not a useful construct in understanding an individual's overall cognitive strengths and weaknesses.

The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act) defines intellectual disability and provides the legal criteria for the diagnosis in New Zealand. Neither the ICD-11 nor the DSM-5TR (that places a greater emphasis on adaptive functioning for identification of severity of the intellectual disability) provide the required criteria for diagnostic assessment for the purposes of access to disability support funded services in New Zealand. Psychologists should always remain within the guidelines in any relevant test manual and the IDCCR Act. Any deviation from standard protocol must be supported by robust clinical rationale and outlined in the report to NASC coordinators or managers.

It is sometimes helpful to outline the eligibility criteria (such as this guideline or Section 7 of the IDCCR Act) and offer some explanation in the text of the report<sup>6</sup>.

Regarding onset, it is important for NASC to know when a client meets criteria for age of onset but has their disability resulting from an acquired brain injury, early onset major mental illness or otherwise. This will not affect their eligibility for services, but some NASC regions have specialised facilities and resources available to them.

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<sup>6</sup> See Appendix 3

A list of the psychometric assessment tools that are currently considered technically superior by international standards is attached to this guideline<sup>7</sup>, including information about each measure that can be used as a summary of these. Relevant summary information can be appended to or embedded in reports, discussing both administration and interpretation of such measures. This reduces the length of the body of reports and allows a reference point for those seeking more in-depth understanding of these tools.

People who sustained cognitive impairment after the developmental period, do not meet criteria for intellectual disability and are not eligible for intellectual disability services.

Regarding the third criterion, if despite your best efforts no information can be gained about a person's developmental history, then it is necessary to establish if any events have occurred during adulthood that may have lowered intellectual and adaptive functioning from premorbid levels, (i.e., prior to the age of 18 years). Such events may include acquired brain injury, poorly controlled psychiatric disorders and treatment for the same, medical or neurological condition, substance abuse and institutionalisation.

Any opinion about the presence of an intellectual disability or otherwise may be further examined, either by a NASC, another agency, or within the Courts. A review of your work does not mean that you did a poor job initially, just that a review has been requested, perhaps in light of new information or new processes (such as CPMIP/IDCCR Act processes). The key issue if findings are challenged is whether you did what a "reasonable professional" in your position would have done and is within current best practice guidelines with the information you had available. While these reviews may be somewhat stressful if they do occur, they do not need to be aversive. People change over time, and new information comes to light. It is suggested that psychologists do not remain adamant about previously expressed opinions just for the sake of it, but to consider their opinion in a professional manner, sometimes in the light of new information or new data.

### Case Examples

*John (48) was recently released from prison and his probation worker requested an eligibility assessment because they were concerned about his level of functioning. John scored 72 on the WAIS-IV. An assessment of his adaptive functioning (using the ABAS-3) suggested extremely low functioning in the self-care, home-living and self-direction skill areas. Wider assessment revealed a high level of substance use since John's son was killed when he was 28. He had been unemployed before being imprisoned but before that worked as a labourer for five years, in a supermarket delicatessen for three years, and as a cleaner for two years. John had never previously received disability supports. John reported some difficulties with attention at school and was suspended once, but his school records suggested he was educated in mainstream classes. John was not diagnosed with an intellectual disability. Whilst his true IQ could have been 72 or below it was not possible to rule out at least some influence of chronic substance use. Also, there was limited evidence of permanent impairment in the developmental period and John's varied work history, without extra support in the workplace, was considered uncharacteristic of intellectual disability.*

*Hinemoa (35) was referred for an eligibility assessment because she seemed to be coping quite independently in disability services (independent supported living) and there had never been a formal assessment of her intelligence or adaptive functioning. Hinemoa scored 71 on the WAIS-IV. An assessment of her adaptive functioning (using the ABAS-3) suggested that whilst she was coping well with support, if she were completely independent, she would struggle with functional academics, self-direction and community use. Wider assessment suggested a high level of support throughout her life. She was educated in special classes throughout school and her support workers and family described how she could develop skills with repeated practice but struggled when she had to deviate from her sequence or routine. Hinemoa continued to enjoy reading, word searches and particularly liked quiz shows on television. Hinemoa's eligibility for intellectual disability support was confirmed. It was notable that she continued to struggle with some aspects of independent functioning despite rich support throughout her life. Her IQ score was understood in the context of a permanent impairment limiting her intelligence despite good attendance at school, an enriching environment that maximised her acquisition of skills and an absence of confounding variables.*

### IQ Stability Over Time:

#### Note for Psychologists

#### The Flynn Effect

<sup>7</sup> Psychometric Tools Appendix 4

The Flynn Effect (IQ Gains Over Time) describes the phenomenon that over the years since IQ testing began, the general level of tested intellectual functioning is slowly increasing, with a generally accepted average of 0.3IQ points per year. This is why tests need to be re-normed on a fairly regular basis. It is ethical clinical practice to use the most recent version of a reliable and appropriate individually administered intelligence test, without obsolete norms. The Flynn Effect should only be perceived as being of any note when older norms are used<sup>8</sup>. Caution should be maintained whenever applying the Flynn effect to the data of any individual as this is a process noted in group data.

Adjusting data further by assuming the Flynn Effect has continued since the standardisation of the most recent intelligence test has been discouraged in a Technical Report by Pearson Education, 2008<sup>9</sup>. Research suggests that the Flynn Effect is no longer evident in Scandinavia. The assumption that the Flynn Effect is continuing is therefore speculative at best. It is likely that the effect was mediated by the population becoming more adept and au fait with this kind of testing or the types of skills measured by modern tests.

Where these issues arise, psychologists should refer to the relevant text (Flynn, 2006<sup>10</sup> and Flynn 2010<sup>11</sup>) and should discuss the matter in supervision with a person skilled in the interpretation of psychometric assessments of intellectual functioning.

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<sup>8</sup> See Schalock, R.L. et al (2010) *Intellectual Disability: Definition, Classification, and Systems of Support: The 11<sup>th</sup> Edition of the AAIDD Definition Manual*. Washington DC: American Association on Intellectual and Developmental Disabilities.

<sup>9</sup> Weiss, L.G. (2008). WAIS-III Technical Report, Response to Flynn. Pearson Education.

<sup>10</sup> Flynn, J.R. (2006). Tethering the elephant: Capital cases, IQ, and the Flynn Effect. *Psychology, Public Policy, and Law*, 12(2), 170-189.

<sup>11</sup> Flynn, J.R. (2010). The Spectacles through which I see the IQ Debate. *Intelligence* 38 (2010) 363–366.



## The Assessment of Children and Adolescents

Intellectual development can be impeded or facilitated by the psychosocial and physical environment. IQ is not an entirely stable construct in the formative period. Trauma, neglect and disrupted education can impede performance on IQ tests with individuals making subsequent and significant gains in more enriching environments. It is important for families, support staff, and professionals to understand that there is potential for change, and that different children and young people have intellectual and cognitive developmental changes at different times. The process of cognitive development continues throughout early adulthood.

This means that children, adolescents and young adults, particularly those previously measured in the mild intellectual disability range of functioning, could potentially transcend the diagnosis. Most commonly, when the child, adolescent or young adult has experienced environmental deprivation and is subsequently supported to gain new experiences and increase their adaptive functioning skills. A false positive diagnosis of intellectual disability can also result from undetected poor effort in testing or if respondents in assessments of adaptive functioning are motivated to under-represent a participant's abilities. For these reasons, children and young adults should be given interim eligibility on the basis they could outgrow the need for disability support. Intellectual disability should only be considered a 'lifelong' and permanent diagnosis in those with more severe disabilities or those who have been **comprehensively** assessed after the developmental period (i.e., during adulthood).

**Children four and under:** It is not always possible or useful to psychometrically assess very young children. If intellectual disability services are required for children in this age group, referrals can be accepted from paediatricians and other allied health specialists who can make a diagnosis of global developmental delay.

**Children and adolescents between the ages of five and 18:** It is possible and advisable to provide comprehensive psychometric assessments for people in this age range, especially those who score towards the upper IQ threshold for a diagnosis of intellectual disability. These cases can sometimes be complex, and people may require multiple assessment visits to develop a broad understanding of the person's situation, as well as completing the necessary psychometrics. All available supports should be delivered to maximise the opportunity to gain skills that will later allow maximum independence and the opportunity to function outside the intellectual disability range.

Adolescents in the criminal justice system are particularly prone to low motivation and they often find it more difficult to develop a trusting relationship with a Court appointed assessor. These factors can easily result in under-performance in formal testing. Furthermore, families or agencies can be invested in continued service provision in an attempt to secure the perceived best outcome for the individual. This further indicates the use of effort testing in assessments and seeking respondents inside and outside the family or wider agencies to complete objective assessments of adaptive functioning. Adolescents involved in the criminal justice system are also more likely to have experienced disrupted education, environments that expose them to less complex language, trauma and chronic substance use. These are all factors that can diminish performance on IQ tests but do not necessarily signal the broad limitation on mastering skills typical of intellectual disability.

### Notes for NASC

NASC should accept referrals from paediatricians for the diagnostic criterion Global Developmental Delay (GDD) for those under four years of age. Any child with the diagnosis of GDD should be reassessed after the age of five years to establish if there are other diagnoses, such as intellectual disability or autism, which should be considered. GDD should not be regarded as a valid ongoing diagnosis after the age of five.

Families and referrers should be made aware that this is 'provisional eligibility' and that accepting children for services with this diagnosis does not automatically entitle them to services for life. A provisional diagnosis should only be for a short amount of time – this means that a comprehensive assessment is required at an appropriate time and ideally within the early childhood years (before age 9).

Families should also be aware that services are provided at the current time, and that further assessments will need to be completed at a later date to establish if the diagnosis remains or has been outgrown.

## Notes for Psychologists and other Health Professionals

Eligibility for children four and under is provisional until such time as comprehensive psychometric assessment or other eligibility evidence is available.

Development continues throughout early adulthood, and diagnosis of any person at, or close to, the developmental period should be made with caution. This should be made as an interim diagnosis, unless there is clear evidence the person meets all criteria without confounding factors (whether personal or environmental). A thorough clinical assessment allows the psychologist to carefully consider the role of confounding variables on test performance and, from that, determine the best supported hypothesis (i.e., whether the person's difficulties are sufficient to meet criteria and are due to permanent impairment). The psychologist should carefully examine for the presence of behaviour that would normally be considered maladaptive, but which could reflect adaptations to a dysfunctional environment that might not be expected from someone with a permanent limitation on skill acquisition.

The General Ability Index (GAI) can be useful to calculate and interpret alongside the FSIQ when the psychologist considers that an individual's FSIQ has been unduly impacted by outlying (lower) scores on Working Memory and Processing Speed subtests, normally due to ADHD or specific learning difficulties (i.e., dyslexia). It is not advised to use the GAI to diagnose (or withhold diagnosis for) an intellectual disability without very careful clinical consideration. It is suggested that psychologists contemplating using the GAI within an assessment consult the advice from Pearson Clinical and ensure that their practice is consistent with that advice, and the reasons for using the GAI in preference to the FSIQ are well explained.

## Case Examples

*Wiremu was diagnosed with an intellectual disability and ADHD at the age of eight. When he was 15 years old an additional eligibility assessment was requested by the Youth Court to assist in determining potential disposition options for him. At the first assessment he struggled to maintain focus on a discussion about his situation or on the test materials presented to him, failing a formal test of effort in the process. After consultation with his psychiatrist, Wiremu was prescribed medication for ADHD which saw an improvement in his ability to sustain attention. Wiremu was then better able to attend to the assessment (an impression supported by additional effort testing) and achieved a FSIQ score of 73. In completing an assessment of adaptive functioning, two respondents rated his Functional Academics and Communication Skills just within the extremely low range. Further assessment revealed very low school attendance in the previous four years (approximately 25%) and mastery of a range of outdoor skills. Multiple sources confirmed he was able to train a hunting dog independently, properly maintain a rifle and drive a 4x4 on bush tracks with a moderate level of skill. He was also popular with his peers and considered the instigator in the offending that led to his appearance in the Youth Court. Wiremu's modest IQ scores were at least partially attributable to disrupted education (rather than permanent impairment alone) and there was clear evidence of adaptation to his circumstances. Wiremu was considered not to meet the eligibility criteria for intellectual disability.*

*Chantelle (11 years old) was referred to a psychologist for an eligibility assessment by the local NASC after concerns were raised by her parents and teacher about her progress at school. Chantelle was cooperative and she reported that she enjoyed the assessment process. Effort testing supported the impression she was interested in testing and determined to achieve well. She scored 70 on the WISC-V with an even profile of scores across composites. Her mother and teacher both rated her adaptive functioning in the extremely low range in seven of the nine skill areas assessed. Further assessment suggested Chantelle's family had attempted to remediate her progress through additional help at school and by developing visual aids to help her complete basic tasks. Chantelle was given an interim diagnosis of intellectual disability because, despite an IQ score at the upper threshold of the extremely low range, her ability to acquire skills was significantly impaired, despite an optimal environment. A recommendation for retesting in three years was made so her response to additional supports (and her general cognitive development) could be gauged in the future.*

## Intellectual Disability Eligibility Assessment

### ***What is an Intellectual Disability Eligibility Assessment?***

An intellectual disability eligibility assessment is a process undertaken in order to establish one of the eligibility criteria for access to services specifically contracted by the Ministry of Health for people with intellectual disabilities. The formal evaluation is undertaken by a psychologist or other suitably qualified

professional to establish if a person has an intellectual disability. The definition and classification of intellectual disability are outlined in section 7 of the IDCCR Act. The American Association of Intellectual and Developmental Disabilities (2010) publication emphasises the importance of clinical judgement and experience exercised by professionals throughout the process of gathering and interpreting information to reach the formal diagnostic decision.

### ***Why Assess Intellectual Disability:***

The New Zealand Government purchases Disability Support Services to those who meet the cabinet criteria for eligible service users. These services are designed to maximise the participation and independence of people with disabilities and support them in full community participation.

The NASC brokers several services available to people with a variety of disabilities. All these services have criteria for eligibility. Many of these criteria are easily established, such as age or evidence of disability (e.g., GP confirmation of a sensory disability). However, the Ministry of Health has purchased some services specifically for people with intellectual disabilities. These include Carer Support, Respite Care, Buddy Support, Community Participation, Home Help, Residential Care, Behaviour Support, Social Work and so on. All these services have criteria for eligibility. However, the Ministry of Health has funded some services specifically for people with intellectual disabilities and their family/whānau. Therefore, those seeking access to these services must satisfy the entry criteria.

A significant component of the diagnosis of intellectual disability is based on psychometric tests. IQ testing is best understood as an imperfect proxy to general intelligence and is part of a comprehensive assessment, not an assessment in and of itself. Many people, particularly those with limited knowledge of psychometric testing, can be sceptical about the use and accuracy of these tools to determine eligibility and diagnosis. For this reason, it is important for psychologists to present their rationale and methodology for such tools to reach their decision, and to discuss both the advantages and limitations of using such measures in their evaluation. These assessments should not be taken lightly as they are likely to substantially impact on important decisions.

It is important to be satisfied that the use of these tests leads to better decisions and conclusions than would have been achieved without them. Murphy and Davidshofer (2014) state that based on information from a special panel of the National Academy of Sciences:

*“Although psychological tests are far from perfect, they represent the best, fairest and most accurate technology available for making many important decisions about individuals.” (p. 2)*

A list of the tools considered technically superior, for this purpose, by international standards, is attached to this guideline<sup>12</sup>.

Establishing the presence of an intellectual disability is not a simple process. Brief intelligence screening tests or group tests may result in scores that are not reliable or valid indicators of a person's actual intellectual functioning. Psychometric, statistical, and clinical evaluative tools have been developed to enable clinicians to make a more objective diagnosis to establish if an individual meets the definition of an intellectual disability. It is important to use the process of accurate data gathering to establish such a diagnosis.

It is important to ensure that people have an intellectual disability before they access the services funded for this group for the following reasons:

- Services have been developed specifically to meet the needs of individuals with intellectual disabilities. These services have not been designed for clients with other support needs. Some clients may have needs in addition to their intellectual disability that may also need to be met.
- There are limited resources, and they need to be protected for the group for whom they have been allocated.
- Service provision by its very nature can limit potential for people to exercise personal choice and live in the least restrictive environment. Only those individuals who genuinely require additional

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<sup>12</sup> Psychometric Tools Appendix 4

specialist supports are likely to benefit from them. Any decision relating to eligibility and access to service should reflect the best interests of the person concerned.

**NOTE: What to do if an eligibility assessment has been completed and it is determined that the person does not have an intellectual disability but may have another form of disability:** Other issues that may arise during an eligibility assessment may include the presence or suspicion of acquired brain injury, mental health issues, physical disability, or autism spectrum disorder. These findings should be detailed in the report to the NASC. This will allow the service coordinator to refer this person to the appropriate support agency or for additional assessment. The absence of an intellectual disability does not eliminate the opportunity to receive other NASC services if they meet criteria; it only precludes those services specifically provided for those with an intellectual disability.

#### Notes for NASC

It is not necessary to ask for an eligibility assessment for every person accessing NASC intellectual disability services, whether or not there is psychometric data available. The presence of a moderate or severe intellectual disability is usually apparent without assessment, and you can often observe this in your contact with the person. There are also some clients with sufficient documentation from GPs and other specialists such as neurologists and paediatricians to be able to conclude that they are much more likely than not to have an intellectual disability.

Look for evidence of prior testing. If testing was completed when the individual was a child and the individual is now an adult, or previous testing was incomplete, then it may be appropriate to request a further assessment.

If you are unable to confirm previous diagnosis, if insufficient assessment data are available or if sufficient doubt exists as to whether or not a person is eligible (taking your observations and other documentation into account), request an Eligibility Assessment. This assessment will be funded through your contracted eligibility provider. If you are unsure about this, discuss with your NASC Manager.

Always provide prior assessments and other relevant documentation (e.g., letters from paediatricians) to the Eligibility Assessor as this may assist in the prevention of unnecessary testing.

The presence of an intellectual disability does not necessarily equate the provision of intellectual disability resources. The question that remains to be asked is whether the client has disability related needs that would benefit from disability support services and what type of service is likely to best meet their needs.

#### Notes for Psychologists

**“Psychologists evaluate clinical impressions from an interview, behavioural observations, and informal assessment, with the added benefit of comparing the individual’s test performance to norms. Indeed, the integration of divergent sources of information with test findings that draws upon the unique skills of the professional psychologist” (Sweet, 2016, p.857). Psychologists need to be able to consider the information they collect in light of alternative hypotheses and make reasoned arguments, acknowledging the intrinsic limitations of the psychometrics available to us (e.g., self-report assessment of adaptive functioning are susceptible to respondent bias).**

When establishing a diagnosis of intellectual disability, it is not appropriate to use an abbreviated or screening measure only. Screening assessments, such as the Hayes Ability Screening Index (HASI), can indicate whether a comprehensive assessment is advised.

If you discover an assessment has only recently been completed, and the conclusions are provided in psychological reports that meet the criteria outlined in this document, it is not necessary to repeat the testing if you are confident that the previous assessment is likely to be a valid and reliable assessment of the person’s optimal functioning. Please request that this information be provided to the NASC or write a summary report accordingly.

Incorporate effort testing into *all* neuropsychological assessment. Recommended tests are the Medical Symptom Validity Test (MSVT), and Test of Memory Malingering (TOMM). Because these tests are often used in medico-legal assessments, reporting of the outcome of these tests needs to maintain test security and should not include the specific test name. Examples of reporting may be, “prior to this assessment, a two-phase indicator of effort was administered, and there were no concerns noted with this” or “the client scored extremely low on certain tests that are objectively quite easy yet scored much higher on more difficult items. This indicates inconsistent performance and insufficient effort to produce valid test results”.

It is important for the person being assessed to know that there may be implications if they do not do their best during the assessment. In New Zealand there has been at least one person who has been convicted of perverting the course of justice for malingering during a psychometric assessment. He did this, reportedly, on advice from his lawyer so that he could receive services through the IDCCR Act, instead of going to prison (R v RH, 2010). It is also important for the person being assessed to be aware of additional implications that can include the possibility of being offered services that are not matched to their needs.

Preferred intelligence tests are the most recent versions of the Wechsler range of intelligence tests and the Stanford Binet Intelligence Scale.

If significant difficulties in assessment are noted, the following alternatives, amongst others, could be considered as a screen:

- Extreme poor concentration span: Wechsler Abbreviated Scale of Intelligence, Test of Nonverbal Intelligence, Fourth Edition (TONI-IV), Raven's Progressive Matrices Second Edition (Raven's 2),
- Poor motor and verbal skills, use of communication book, tests that accommodate for pointing only: TONI-IV, Comprehensive Test of Nonverbal Intelligence (CTONI-2), Peabody Picture Vocabulary Test, Fourth Edition, Raven's 2.
- Visually impaired: Wechsler Adult Intelligence Scale Fourth Edition (WAIS-IV) and Wechsler Intelligence Scale for Children Fifth Edition (WISC-V) Verbal Comprehension and Working Memory indices, adapted SIB-R adaptive behaviour assessment,
- Hearing impaired (use an appropriate interpreter): WAIS-IV/WISC-V nonverbal indices, i.e., Perceptual Reasoning and Processing Speed, see also WAIS-III technical manual p.178; TONI-IV, CTONI-2, Raven's 2.

The use of any of these measures instead of a comprehensive measure of intellectual functioning should be done with caution, appropriate caveats, and robust clinical discussion of other factors about the person that support or refute your hypothesis about intellectual functioning. They should be used only when the recommended comprehensive tests are not able to be administered or interpreted in a valid or reliable manner. Discussion of the limited validity of the above tests must be contained in any report and conclusions should be provisional.

Avoid using the Wechsler Abbreviated Scale of Intelligence in clinical situations as administering this may result in some issues with test-retest reliability of a comprehensive Wechsler measure if required later. No screen can be used to confirm the presence of extremely low intellectual functioning on its own.

Recommended adaptive behaviour assessments include the most recent versions of the Vineland Adaptive Behavior Scales (Vineland) and the Adaptive Behavior Assessment System (ABAS). Consideration of different measures, such as the Scales of Independent Behavior (SIB), should take age range, breadth of areas assessed, and age of norms into account. As with intelligence tests, psychologists should carefully consider the influence of confounding variables (i.e., other than permanent impairment) on the acquisition of daily living skills. These can include physical disabilities, substance abuse, and cultural factors. In addition, psychologists should note that self- and other-report assessments of adaptive functioning are subject to respondent bias. Measures of adaptive functioning should detect actual independent skills, not motivation. Therefore, the question is not how often a person can independently complete a task but how often they could do that task if they really needed to.

If a person is mentally unwell (e.g., experiencing overt symptoms of psychosis, mania, or other significant disorder), the psychologist needs to wait until the person is mentally well before completing a psychometric assessment in order to establish an intellectual disability. Any psychometric assessment of a person who is actively mentally impaired is unlikely to provide data that is a valid representation of their best performance.

Individuals may be unable to have a valid psychometric assessment if these issues (amongst others) are present: severe or profound intellectual disability, significant behavioural issues, other significant disability (e.g., autism, concurrent dementia, chronic mental illness with severe impairment such as significant perseverations, catatonia, latency of speech). If upon assessment you discover the client's presentation means they are too severely impaired to assess, please refer to the guidelines offered in DSM-5TR Unspecified Intellectual Disability and notify the NASC accordingly.

If a full assessment is unable to be completed, please summarise your findings for the NASC and discuss possible alternatives to establish diagnosis.

While previous advice had been to be cautious about reporting the FSIQ if there was a significant scatter in a person's IQ profile, the FSIQ is the greatest predictor of actual intellectual functioning regardless of the scatter. If there is such scatter (more than 23 points, or 1.5 standard deviations), it is appropriate to

discuss the varied range of abilities in addition to the FSIQ. Crowe (2010) provides further information about this matter<sup>13</sup>.

## ***When should a report be requested?***

An eligibility assessment should be requested when a NASC Service Coordinator is in doubt as to whether or not a person has an intellectual disability. **Where there is clear evidence, do not request another eligibility assessment.**

Clear evidence would include a diagnosis, at any age, of moderate or severe intellectual disability by a health practitioner able to give such a diagnosis; a comprehensive psychological report completed within the previous few years that includes psychometric data that indicates the person meets all three criteria; a paediatrician's or health practitioner's report for a young child (aged four and under) indicating marked developmental delay.

Clear evidence of an intellectual disability can sometimes be gained from interaction with the person. If a person has had a lifetime of being functionally non-verbal, is highly dependent on others to complete basic tasks for them, has had significant supports throughout the education system (or, rarely, has been unable to be included in the education system), and is at an age when this level of functioning is extremely unusual, then it is possible to conclude that they have an intellectual disability without requiring a psychometric assessment. The NASC coordinator is advised to discuss each person with this presentation with their manager prior to concluding that such a diagnosis exists without requiring psychometrics.

### **Case Example**

*Timoti presented as a tall and slim Māori man who appeared somewhat younger than his 25 years of age. He was dressed in casual clothes and wore a cap throughout the assessment. He had prominent top teeth that were more obvious because of his frequent smiles. Timoti's significant impairment was clear from first interactions with him, as indicated by his limited vocalisations, which were often fast paced and relatively loud, although he responded well to prompts from his mother to use his "indoor voice", and his language, which involved several repeated one- or two- word phrases, such as being excited about doing some puzzles, and was very basic in content. He gave a warm greeting and a handshake with a loose grip. He was able to repeat my name immediately after he was informed what it was twice, although forgot it immediately afterwards. He sat on the stairs in the lounge and frequently waved and smiled at me while his mother provided information about his current situation and his past. A good level of rapport was easily developed. At one point in the assessment process Timoti asked if I loved him. He responded well to being informed that as I had only just met him, I did not love him, but enjoyed being there with him at that time. Timoti was induced six weeks prior to the due date because of failure to thrive and he required forceps delivery, weighing 4lb4oz. All his developmental milestones were significantly delayed. He continues to be incontinent of faeces if he is not prompted to use the toilet regularly. He received a high level of ORS funding at school and remained at a Special School until the end of the year when he turned 21 years old. He has not had any employment or voluntary work, nor has he been involved with any vocational service. He has, instead, been cared for by members of his whānau and marae since he left school. He is a well-loved young man with no behaviours of concern, nor has he any mental health difficulties nor any history of trauma or abuse.*

If adults present with assessments that were completed when they were children, the NASC needs to consider the quality of the assessment that was completed in relation to these guidelines (a paediatrician report, for a person four years and under, is not acceptable). This consideration should

<sup>13</sup> Simon Crowe in *Evidence of Absence, A guide to cognitive assessment in Australia* (2010) and referring to the use of the WAIS IV

note particularly how comprehensive the assessment was, the person's behaviour and mental state at the time of assessment, how long ago it was completed, and the level of intellectual disability identified. For reasons already noted, careful consideration should be given to historical assessments of mild intellectual disability and generally a reassessment on reaching adulthood as indicated.

## **How an ID Eligibility Assessment should be undertaken**

### ***Access and Referral:***

Any person can request a Needs Assessment from a NASC; however, requests for intellectual disability eligibility assessments are generated by the NASC themselves. Agencies and families do not have the ability to request such an assessment (unless they choose to do so in a private capacity and fund this themselves). The NASC makes a request for such an assessment if they believe the person needs services and requires eligibility for those services to be established. If information pertaining to the presence of an intellectual disability is already available, the referrer should make this available to the NASC when the referral for Needs Assessment is made.

### ***What should a request for Assessment include?***

The request for an eligibility assessment needs to be specific and should be accompanied by appropriate supporting documentation. The request should state identifying information and supply contact details for the person and an appropriate alternative contact or support person. The request should specifically ask for an intellectual disability eligibility assessment to be undertaken to determine eligibility to receive a needs assessment and potentially service coordination through NASC.

#### **Notes for NASC**

Be specific in your request. State that you are requesting an assessment of intelligence and adaptive functioning plus a description of the person's functioning during their developmental years, to determine if the person has an intellectual disability. Explain that this diagnosis is required to establish the person's eligibility to receive a needs assessment for specialised intellectual disability services or resources.

Include accurate contact details and a statement on (ability to) consent / assent and details if the person has a welfare guardian or activated enduring power of attorney.

Documentation that would be of assistance to the psychologist may include recent needs assessments, any previous assessments, social history, school records, and other professional / medical assessments.

When an initial request for an intellectual disability eligibility assessment is made to a psychologist, make the request of an appropriately qualified and experienced person. You may like to ask if they are currently, or have previously, practised specifically in the area of intellectual disability, are a registered psychologist, and have NZCER test user registration level C. It is unlikely that any psychologist would mind offering their credentials. If anyone is unsure you could offer these guidelines as support.

#### **Notes for Psychologists**

If you do not feel you have a clear request for services, or you do not have sufficient information to commence an assessment, then contact the referrer.

Please refer to your own Code of Ethics, as well as NZCER and Pearson Clinical guidelines, for information on appropriate training and expertise.

Psychologists should use professional judgement and not present as experts in the field of intellectual disability and/or psychometric testing unless they have significant and recent expertise in the field or seek appropriate supervision for the assessment.

### ***Role clarification:***

The process for eligibility assessment by a psychologist consists of the review of any available documentation that relates to the person's functioning throughout the developmental period, clinical

interviewing, and psychometric testing. It is the psychologist's task to determine if the person has an intellectual disability or not; this is not the role of NASC. It is the NASC's role to screen whether the assessment meets the generally accepted standard (i.e., the three criteria of intellectual disability are discussed, met and attributed to permanent impairment), complete a needs assessment, identify the necessary supports, and put these in place if eligibility is determined. If they are not satisfied with the standard of a report, the NASC is advised to speak with the assessing psychologist in the first instance and, if necessary, a second opinion by an appropriately qualified person may be sought. A psychologist might make recommendations within the eligibility assessment report, but this is not the primary purpose of this assessment. Recommendations by a psychologist might include further specialist assessment activity, the addressing of safety issues, or actions that might be taken to address specific support needs.

### ***Who should conduct an assessment?***

According to the New Zealand Psychologists' Code of Ethics (2002) only psychologists practising in their field of expertise should conduct these assessments. In New Zealand, the necessary credentials for conducting formal eligibility assessments are being a Registered Psychologist with a clinical or educational scope of practice and/or the qualifications required to meet the criteria of level C test user registration.

If the person's diagnosis could be used in a judicial setting, and it should be kept in mind that this could happen at any time after the assessment, the assessor must abide by the criteria set out in the New Zealand High Court Rules (schedule 4) for providing expert evidence (refer to appendix 5).

### ***Sharing of information gathered for assessment and reports:***

One of the main aims of this document is to establish consistency and reliability of intellectual disability assessments. The reason for this is that if there are benchmark standards for these assessments, it will eliminate much of the need for repeat assessments. Psychologists and allied health professionals are asked to share psychometric and assessment data with their peers in accordance with their own Codes of Conduct.

### ***People found not to have an intellectual disability:***

If someone is found not to have an intellectual disability when they are first assessed, NASC are to notify the person and/or their family of the outcome of the assessment.

If upon reassessment a person is found to no longer meet the criteria for an intellectual disability, this may be due to several factors, including improved well-being, positive task-oriented behaviour at the second or subsequent assessment, a poor standard of initial or current assessment, or the presence of interim supports and motivation that have lifted the person's cognitive and/or adaptive functioning above the range required for the diagnosis of an intellectual disability.

NASC services have the responsibility to transition-to-exit existing clients who are no longer eligible for disability support services for people with intellectual disability or no longer require services. This should be done in a measured manner, to help the person to cope throughout the transition from the disability support framework. The process includes assessing whether these clients may be eligible for other Ministry funded support services.

**NOTE: What to do if an eligibility assessment has been completed and it is determined that the person does not have an intellectual disability but may have another form of disability:** Other issues that may arise during an eligibility assessment may include the presence or suspicion of: acquired brain injury, mental health issues, physical disability, autistic spectrum disorder, or significant life events including trauma, abuse and environmental deprivation. These findings should be detailed in the report to the NASC. This will allow the service coordinator to refer this person to the appropriate support agency or for additional assessment. The absence of an intellectual disability does not eliminate



the opportunity to receive other NASC services if the individual meets criteria for those services; it only precludes those services specifically provided for those with an intellectual disability.

#### **Notes for NASC**

The NASC should notify the individual concerned and their whānau/guardian of the outcome of the assessment and refer them to alternative providers or other agencies where appropriate.

The person remains under NASC jurisdiction until a conclusion has been reached.

If you are concerned that there is a poor standard in the current assessment or are unsure about any of the content, approach the psychologist who completed the assessment, and discuss your concerns. If you do not come to a satisfactory result, consider obtaining a second opinion or review of the assessment.

#### **Notes for Psychologists**

When a finding of no intellectual disability is made, the psychologist should still provide a report.

If you assess someone who has previously been diagnosed with an intellectual disability, and your assessment indicates that they no longer meet criteria for that diagnosis, please review your own assessment procedure and conclusions with an experienced colleague or supervisor. If the previous assessment was completed recently, it is also recommended to contact the original assessor to discuss the difference in results. If you confirm your findings, state the reasons for them clearly in the report, and make any relevant recommendations. These recommendations may assist the NASC to help support the person to transition out of services or to obtain other relevant services.

It is advised to comment on the possible reasons for the difference in measurement over time. This may be helpful for the person or their family to understand the reasons why the person or their family member may not have an intellectual disability, despite the difficulties they are or have been facing, and what alternative diagnoses may be applicable.

## Intellectual disability eligibility reports

### ***What a report should detail:***

There is no one specific format that is or should be required for reports of these assessments<sup>14</sup>, although there are basic requirements that should be met by each report. A report should outline:

- Date of the report, date of the assessment.
- Demographic information.
- Who requested the assessment and what was requested.
- How consent was obtained.
- Sources of information: people and documentation consulted.
- Current observations and mental state assessment, comment on reliability of current assessment.
- Personal history and background information: family history, gestational and birth history, developmental milestones, educational history, employment, language, cultural and spiritual history, previous service or specialist involvement, medical conditions and medication, other diagnoses, significant life events, social and behavioural issues, alcohol and drug use, sexual and relationship history.
- Comment on rapport, formally test effort and provide comment on the validity of results.
- Psychometric test information and interpreted results.
- Any relevant findings that have bearing on the referral question.
- Summary and conclusions, including a clear statement as to whether or not the person meets the three required diagnostic criteria, attribute those findings to permanent impairment and therefore whether they have an intellectual disability (or whether a provisional diagnosis is more appropriate, most commonly in the developmental period).
- Recommendations.
- Psychologist's signature and qualifications, letterhead and other contact details.

#### **Notes for NASC**

Eligibility outcomes should always be provided to you in report format in accordance with guidelines offered above, and not verbally. If you think that not all of the required information is in the report, speak directly with the writer. You may wish to provide a copy of these guidelines.

If the person is found not to have an intellectual disability it is the responsibility of the NASC to inform the person and discuss appropriate options.

If you are concerned that there is a poor standard in the current assessment or are unsure about any of the content, approach the psychologist who completed the assessment, and discuss your concerns. If you do not come to a satisfactory conclusion, consider obtaining a second opinion or review of the assessment.

#### **Notes for Psychologists**

Eligibility reports have been requested for a specific purpose and are contracted on the basis of specific costs and time intervals. If you are asked for more than the requirements of a basic eligibility assessment you need to discuss this with the referrer (you may like to refer to or provide these guidelines).

If, while assessing, you have additional findings and see the need for other areas of work required, make these recommendations additional to your eligibility findings. Do not undertake additional work without consultation with the NASC.

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<sup>14</sup> A suggested eligibility reporting example is attached to this guideline please see Appendix 3. Note, the appended data in this report does not need to be provided to the NASC if it is appropriately explained in the body of the report.

Include the interpreted (i.e., not raw scores) findings of both the cognitive and adaptive behaviour assessments in the report. Provision of raw scores contravenes the code of ethics and can lead to confusion. For example, when scores appear to contradict a diagnosis.

Consider reporting 95% confidence intervals and ranges for intelligence and index scores, as well as adaptive behavioural assessments.

Be specific in your conclusions or recommendations about the outcome (e.g., “Mark is a young man who meets the required criteria to be diagnosed with an intellectual disability.”) Do not assume that NASC staff will reach this conclusion based on psychometric outcomes.

Provide a rationale if standard assessment or testing procedures were not followed.

Be aware when using the classificatory label ‘mild’ when reporting findings. This term can often be interpreted as the person only having a ‘slight’ disability. It may be helpful to offer an explanation of terms or offer percentile ranks.

### ***Who should receive a copy of a report?***

Similar to reports completed for other clinical work, assessment reports relating to intellectual disability eligibility belong to the requesting organisation, in this case the NASC. Psychologists may wish to discuss the findings of a report with the person/whānau, and this should be discussed with the NASC. A copy of the report should only be given to the agency that requested the assessment who will accept responsibility for a copy being sent to the person. This provides a consistent way for recipients to access reports and for following up any queries they may have in relation to their access to services.

Reports may only be given to the person and any legal guardians. Reports can be shared (with appropriate consent) with other allied educational and treating consultants and GPs where the person may benefit from this information being shared. Participation alone does not entitle people to a copy of this report. These documents contain highly personal information and should be treated with all of the appropriate privacy requirements of your organisation. When requested by the Court, the report is the property of the Court and may only be shared with their permission.

## Service access

### ***Services available:***

The Ministry funds the following services for people who have an intellectual disability:

- Supported Independent Living
- Carer Support
- Behaviour Support
- Residential Care
- Respite Care
- Home and Community Support
- and others.

Eligibility for these services is based on the NASC confirmation of two things: eligibility (confirmation of diagnosis) and need. Having an intellectual disability alone does not entitle a person to services. Service users and those referring people with suspected intellectual disability must also be aware that the Ministry provides funded services, not funding.

### ***Regional service availability:***

The Ministry of Health attempts to provide consistent levels of service nationally, however, due to a variety of historical purchasing arrangements, provider contracts, and resource availability, this is not always possible.

Notes for NASC
When offering a regional support service (i.e., one that is not available nationally) you must make this known to the client and their family. People need to know that some services are purchased based on availability, and that despite attempts to make all services available nationally, this is not always possible.
Service availability should always be considered before engaging in inter-NASC transfer. Full eligibility details should always be provided with an inter-NASC transfer. Eligibility is the responsibility of both NASCs, and the receiving NASC should not action a referral until eligibility has been established

Notes for Psychologists
When a client moves to a new region, please be aware that the receiving region may wish to clarify points in historical assessment to check eligibility has been maintained. This is particularly relevant when a person received services as a child and is now an adult who requires confirmation of diagnosis.

### ***FCS(ID) and IDCCR:***

The IDCCR Act came into force in September 2004. The passage of the IDCCR Act created a new system for facilitating the provision of compulsory care and rehabilitation for people with an intellectual disability who come before the criminal justice system and allows for transfer of some people from prison or mental health facilities to the Forensic Coordination Service (Intellectual Disability)<sup>15</sup> (formerly RIDCA).

It is important to note that the eligibility under the IDCCR Act 2003 is the same as the criteria applied in this document for access to intellectual disability services. Reports for eligibility under IDCCR are subject to a much higher level of both legal and clinical scrutiny so they are often more comprehensive and robust in both their methodology and interpretation than standard eligibility assessment reports presented to NASC.

Engagement with the criminal justice system may require this information and other relevant health information to be shared. At these times reference should be made to the Health Information Privacy Code.

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<sup>15</sup> Refer to FCS(ID) Services Specifications

### Notes for NASC

FCS(ID) referrals are the responsibility of the NASC and should contain all relevant eligibility details and copies of eligibility assessments.

### Notes for Psychologists

**A person who has an intellectual disability should not be found to be unfit to stand trial because of that disability alone. People with intellectual disability may be able to stand trial (or able to develop sufficient understanding to participate). Each person requires a comprehensive assessment based on their individual knowledge and ability.**

Proposed Care Recipients may be assessed by the Court under the IDCCR Act and have their intellectual disability confirmed by a Health Assessor or Specialist Assessor. Where the Court has made a decision on evidence of a Health Assessor, a Specialist Assessor may be asked to complete a risk assessment. This occurs after a formal request from FCS(ID). A Specialist Assessor is a psychologist designated by the Director General of Health under section 146 of the IDCCR Act.

If you have completed a comprehensive eligibility assessment in accordance with these guidelines and the client is later referred to the FCS(ID) or comes before the Court, it is possible for your assessment to be used by the Specialist Assessor for the purposes of that process. The Specialist Assessor is responsible for all information provided to the Court and is likely to contact you should this occur.

### ***Dual Diagnosis:***

People who have a concurrent diagnosis, for example intellectual disability and mental illness, need to be assessed by appropriately experienced health professionals. This may include psychologists and be in conjunction with NASCs.

Where a person requires support primarily due to their intellectual disability, the Ministry is responsible for funding support within the range of services in the DSS framework. Mental health services remain responsible for providing mental health assessment and clinical intervention for people who have an intellectual disability and coexisting mental illness. Where it is difficult to determine whether the need for support is primarily due to an intellectual disability or to a mental illness, it is likely that joint/shared funding arrangements may be negotiated. NASCs should discuss these individual situations with their DSS Portfolio Manager.

### ***Request to inter-sector agencies***

The majority of clients seeking intellectual disability services come directly to the attention of the NASC from families or existing disability services. Some clients come to the attention of the wider sector without any prior knowledge or assessment of their intellectual functioning. Examples of this include younger children in schools, those under care of paediatricians, children and adults receiving mental health services, or people presenting to the Courts.

It is helpful if all assessments of cognitive functioning meet consistent standards as outlined in this guideline so that a smooth transition amongst clinical and NASC services can occur. If a psychologist starts administering a specific psychometric measure, it is important that the administration is completed, and a comprehensive report provided. If a psychologist is unable to complete an assessment to that level of detail, then they have a professional obligation to refer to a NASC asking for them to refer elsewhere for a comprehensive eligibility assessment.

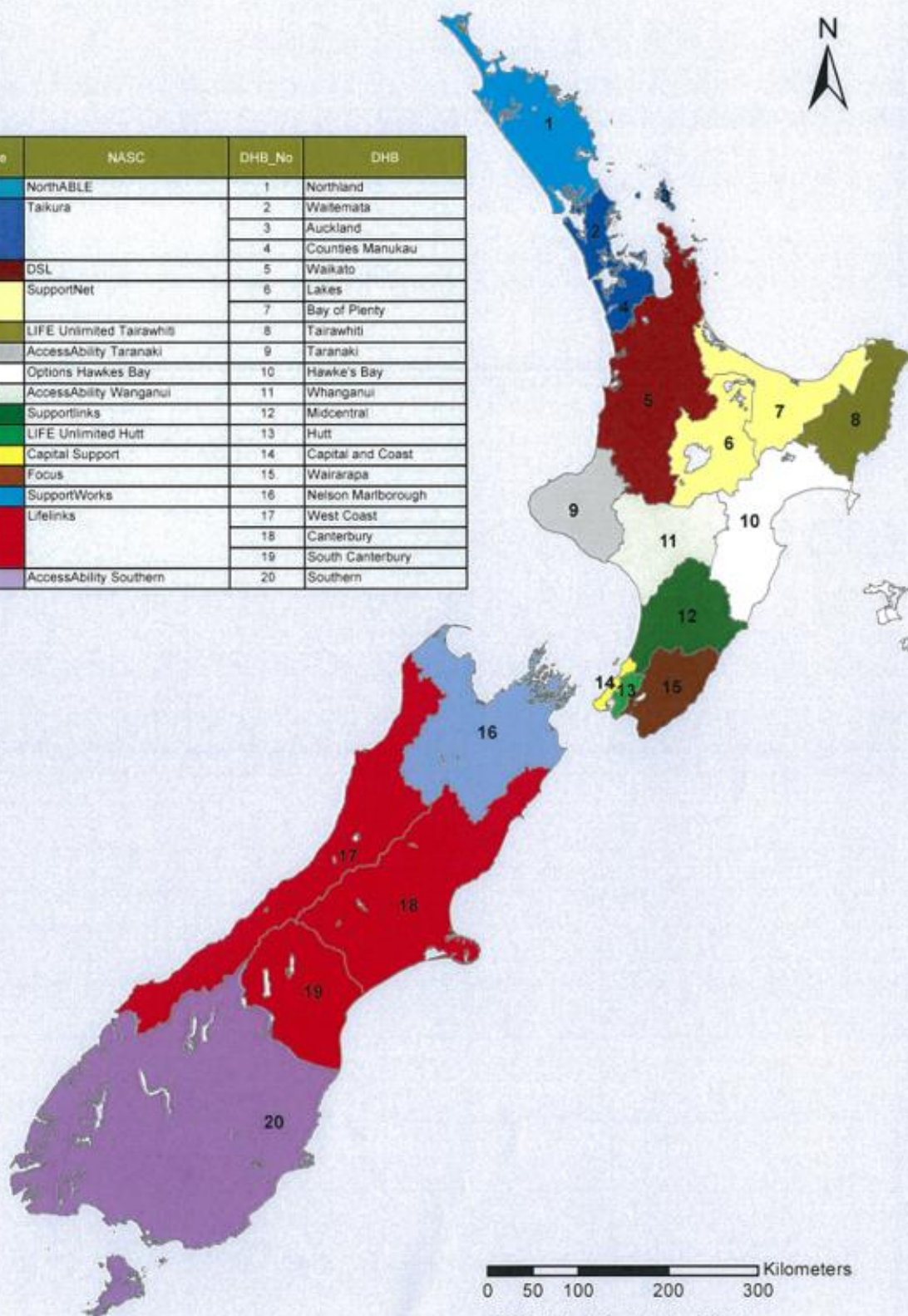
It has been encouraging to see examples of good collaboration and the development of inter-agency relationships over the years. It is the intent of the Ministry in providing this document to enhance this by clarifying requirements and further the relationship development and collaboration.

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## Mapping of DHB Regions to NASC Regions

Code	NASC	DHB_No	DHB
NWD	NorthABLE	1	Northland
NTA	Taikura	2	Waitemata
		3	Auckland
		4	Counties Manukau
		5	Waikato
DSL	DSL	6	Lakes
SNT	SupportNet	7	Bay of Plenty
		8	Tairāwhiti
LUN	LIFE Unlimited Tairāwhiti	9	Taranaki
AAL	AccessAbility Taranaki	10	Hawke's Bay
OHB	Options Hawkes Bay	11	Whanganui
AAW	AccessAbility Wanganui	12	Midcentral
SL	Supportlinks	13	Hutt
LUN	LIFE Unlimited Hutt	14	Capital and Coast
CCS	Capital Support	15	Wairarapa
FOC	Focus	16	Nelson Marlborough
SUW	SupportWorks	17	West Coast
LFL	Lifelinks	18	Canterbury
		19	South Canterbury
		20	Southern
AAO	AccessAbility Southern		





17 June 2014

Dear NASC Manager

### **Operational Guidance for the Assessment of Intellectual Disability to Access Disability Support Services**

Many of you will be aware of discussions occurring relating to the introduction of the fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-V). You may have been asked how this affects Ministry of Health Disability Support Services (DSS) eligibility or have noted some change in clinicians' practices as a consequence. This guidance is intended to explain that this new edition of DSM in no way changes the eligibility criteria for DSS. Eligibility for DSS services is based on both statutory requirements and policy directives set by government. These directives are formed with a significantly wider scope of inclusion than one international text.

A number of diagnostic fields have been re-scoped in this latest edition and clinicians may change their practices in terms of how they describe conditions. The area this is most likely to present to NASC are the changes to the diagnostic description of Intellectual Disability (ID).

In May 2012 the Ministry of Health (the Ministry) issued a revised "Operational Guideline for the Assessment of Intellectual Disability to Access Disability Support Services Contracted for People with Intellectual Disability in New Zealand 2012".

This guideline was developed as a guide for both Needs Assessment Service Coordination Organisations (NASCs) and Psychologists conducting assessments for intellectual disability. The purpose of this document was to establish appropriate and consistent practice in this area of assessment for establishing eligibility to receive services funded by DSS for people with intellectual disability. This guideline was developed using a number of both national and international classificatory systems<sup>1</sup> and details a diagnostic criteria according to the meeting of three requirements for eligibility to access disability support services.

In the guideline the criteria for diagnosis of an ID for the purpose of accessing funded disability support services are:

- **Significantly sub-average intellectual functioning.** This equating to at least two standard deviations lower than the mean (average) on an individually administered IQ test, most of which would result in an IQ of approximately 70 or below.
- **Impaired Adaptive Behaviour.** Deficits or impairments in current adaptive functioning in at least two of the following areas: communication, self-care home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.
- **Evidence of this impairment during the developmental period of the individual.** A period conventionally taken to end at 18.

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<sup>1</sup> Including both the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (2000), the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition draft definition of intellectual disability and the World Health Organization: ICD-10 Classification of Mental and Behavioural Disorders (1993).



New Zealand also has a statutory definition of Intellectual Disability set out in law as specified in section 7, Intellectual Disability (Compulsory Care & Rehabilitation) Act 2003.

### **DSM-V and the diagnosis of Intellectual Disability**

In the fifth edition, Intellectual Disability, also called Intellectual Developmental Disorder in DSM-V, is defined as a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains.

Somewhat controversially while IQ test scores are still seen as relevant, the diagnostic criteria no longer include a cut off figure of less than 70. Instead, stating in the section titled Diagnostic Features *"a person with an IQ score above 70 may have such severe adaptive behaviour problems in social judgement, social understanding, and other areas of adaptive functioning that the person's actual functioning is comparable to that of individuals with a low IQ score"*<sup>2</sup>.

We understand that some clinicians may now be submitting eligibility reports using the DSM-V criteria and basing their diagnosis primarily on impairment in adaptive functioning, even though the individuals' IQ is either assessed, or presumed to be significantly above 70. At this time the Ministry is not looking to update the advice and policy position provided in the Operational Guidance and maintains the diagnostic criteria detailed above as the one required to determine eligibility for DSS.

This letter is therefore being sent to clarify that currently eligibility to access DSS funded services on the basis of an Intellectual Disability remains only available to individuals who meet the diagnostic criteria as provided in the May 2012, Operational Guideline for the Assessment of Intellectual Disability to Access Disability Support Services Contracted for People with Intellectual Disability in New Zealand 2012.

Yours sincerely



Amanda Smith  
**Chief Advisor Disability / Director IDCC&R**  
**National Services Purchasing**  
**National Health Board**  
**Ministry of Health**

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<sup>2</sup> American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

## Appendix Three – Eligibility Report Example

### PSYCHOLOGICAL REPORT

#### DIAGNOSIS OF INTELLECTUAL DISABILITY

**Name:** Rose Greene  
**Address:** 11 Main Street, Midtown  
**Age:** 22 **NHI:** ABC1234  
**Referred by:** M Brown, Needs Assessment & Service Coordination Agency, Midtown  
**Date of Assessment:** 3 March 2022  
**Date of Report:** 8 March 2022

#### REASON FOR ASSESSMENT:

Rose was referred by Mary Brown, for assessment to establish whether she had an intellectual disability and was eligible for supports from disability services for this. An assessment was therefore completed to ascertain if Rose meets the criteria for this diagnosis. The Ministry of Health notes that the criteria are as follows:

- Extremely low intellectual functioning
- Significant deficits in at least two areas of adaptive functioning, and
- That these deficits are current and are likely to have occurred during the developmental period, that is, before the age of 18 years.

Rose was fully informed of the purpose of the assessment and her rights, and she willingly agreed to continue with the procedure as discussed. She also agreed to the subsequent sharing of information that was gathered during the assessment, and particularly that the report would be sent to the referrer.

#### SOURCES OF INFORMATION:

- An interview was completed with Rose and her mother, Theresa.
- The *Wechsler Adult Intelligence Test – Fourth Edition* (WAIS-IV) was used to assess Rose's intellectual functioning.
- A formal test of effort
- The *Adaptive Behavior Assessment System – Third Edition* (ABAS-3) was completed by Theresa to assess Rose's adaptive functioning.

#### PRESENTATION:

Rose presented as a casually dressed woman of slightly bigger than average build in her early twenties. Rose's mother attended most of the assessment session, although left when it was time to complete the assessment of intellectual functioning. Rose appeared comfortable with the process of the assessment, making and sustaining positive eye contact, smiling as appropriate, and responding to questions directed to her when she could. Rose initially appeared unaware of the process that was occurring, although by the end of the four- and half-hour assessment session she was well aware of the purpose and limits of the assessment, being able to discuss the fact that a report would be prepared and would be sent to the referrer. Rose's speech was clear, well-articulated, and with reasonable pace. Her language content was appropriate to the discussion being held.

The amount she discussed varied depending on whether her mother was speaking on her behalf, at which time she would often be quiet, although would at times make clarification statements for her mother, or whether she was answering a question herself. There was no evidence of any disorder of mood, thought or perception, her language remaining on topic and logical at all times, although unsophisticated in content. When the psychometric assessment began, Rose appeared to give her best effort to the items. She would not give up when items were difficult without giving them reasonable effort first.

#### CURRENT SITUATION:

Rose lives with her mother and her stepfather. She has regular contact with her older brother and his wife and two young twin daughters. Rose enjoys all contact with her family, and particularly likes being an aunt to her nieces. Rose regularly spends time with her few good friends over the weekend, participating in activities such as watching movies (she enjoys romantic comedies and action genres), and going shopping (often window shopping). Rose has a number of expected regular tasks to complete in her home, such as dishes, laundry and vacuuming. She is also responsible for maintaining her bedroom in a tidy and clean state. She takes pride in her performance in doing so. She also has a small vegetable and herb garden that she enjoys spending time and

effort working on, and she takes particular pride when her produce is used in family meals. Rose said that she enjoys her life, and has some goals for the future, such as going flatting and getting a job. She sleeps well and has a healthy appetite.

## **PERSONAL HISTORY:**

### **Family, birth, and early development**

Rose is the younger of two children. Her mother Theresa experienced six miscarriages prior to having her older child Chris, and she was then informed that she could never have another child. Mrs Greene did not recognise that she was pregnant until she was six months into her pregnancy when she went to consult a general practitioner to ask for “diet pills” and she was informed of her state. Rose was born in Midtown and weighed 8lb3oz at birth. Mrs Greene said that when she was born, she had the umbilical cord around her neck, she took some time before she cried, and required several “slaps” from the delivery team. This indicates that there is a possibility that Rose may have suffered from some anoxia at birth.

Rose initially had difficulty sleeping and eating. She spent six weeks at Karitane hospital because of eating difficulties. Rose first walked at 13 months of age, and while Mrs Greene could not recall when she talked, she said it was delayed. Mrs Greene did say that Rose had Speech Language Therapy when at school to assist with articulation.

When Rose was nine years old, her parents separated. When Rose was 14, her mother met her current husband, Bob. Bob is a manager of a local construction company, having previously been a builder. Rose said that when her mother started her relationship with Bob, she was uncertain about this, and that she did not want another man in her mother’s life, although she said that she quickly became fond of him and was now quite concerned about Bob’s current health issues (recently diagnosed type 2 diabetes and on-going repeated migraines). Theresa is a florist and works part-time in a local florist shop, which she very much enjoys.

### **Education**

Rose attended kindergarten and was described as an “escapee” as she would frequently return to her home instead of staying there. Her home was on the same block as the kindergarten, so this was easily achieved. She attended Midtown Primary School, and she got on well with the other children there. Theresa reported that the other children in Rose’s classes were generally caring and considerate to her and involved her in social activities as was normal for other children. Rose had support from a teacher’s aide throughout her primary schooling.

She attended Midtown College from forms 1-7, and left school without any formal qualifications. She was in special classes for half of each day throughout her time there. Rose said that when she was at school she was sometimes picked on by other children, particularly boys, although she maintained a close group of female friends who often defended her.

### **Vocation/Employment**

While Rose was at school, she had work experience cleaning cars at a sales yard. After this, Rose worked as a kitchen hand in a local restaurant for a few months as part of work experience. She also reported that she enjoyed having a caring role with many other people, including helping older people with their gardens, and looking after children. Rose has not successfully had on-going employment but would like to find work in a day care facility.

### **Residential**

Rose has spent her whole life living with her family. She said she would like to move into a flat with same age flatmates at some time in the near future.

### **Relationships**

Rose’s most significant relationship is with her mother. She relies on her for support with most of her decision making, although can insist on having her own way at times. Rose has also had two significant intimate relationships. One was when she was at the end of school, and she had a relationship with a young man who appears to have had a degree of disability. This relationship was spoken about with some fondness. She also had another relationship with a male peer when she was twenty, and this developed into a sexual relationship that was generally positive. He moved with his family to Sydney ten months ago. They maintain friendly contact on Facebook but are clear their relationship has ended.

Rose currently has several friends, including one who has been a friend since they attended High School together. She enjoys activities such as walking dogs with her friends, working on gardens to help others, and baking with friends.

### **Cultural and Spiritual**

Rose said she had no important cultural or spiritual practices or beliefs but follows the standard calendar in New Zealand of celebrating Christmas and Easter.

### **Financial**

Rose has all her money managed by her mother and is happy with this arrangement. She is on the supported living benefit, and pays \$150 a week board, and has the rest as spending money, although she is currently saving for furniture for when she goes flatting.

### **Medical**

Rose described her health as OK although she does have mild asthma. She is also on depo provera, which she liked the positive effect it had on her menstruation, although she said she had gained a significant amount of weight since going on it. As she is not currently in a sexual relationship, she is considering stopping the depo provera, and will discuss alternatives to this with her GP and her mother.

### **Psychiatric History**

Rose has had no involvement with mental health services.

### **Alcohol and Drug history**

Rose enjoys an occasional social drink and is fond of wine coolers and shandy. She stated that she had once consumed enough alcohol to suffer the effects of a significant hangover and she never wants to repeat that sensation. She says she has never used marijuana or other illicit substances. She does not smoke cigarettes.

### **Forensic/Offending**

Rose has never been involved with the police or the Court system.

## **CURRENT ASSESSMENT OF INTELLECTUAL AND ADAPTIVE FUNCTIONING:**

In order to establish if Rose has an intellectual disability, Rose was administered the **Wechsler Adult Intelligence Scale, Fourth Edition**<sup>16</sup> and a formal test of effort. Rose's behaviour during the current assessment was cooperative and she was able to maintain concentration and attention throughout. She did not give up on difficult items and appeared to work to the best of her ability. The subjective impression she gave of applying effort in testing was supported by formal effort testing. It is likely, therefore, that her results indicate her true ability level. The assessment provides a "snapshot" of how well Rose performed on that day. There were no situational or personal factors present during the assessment that are likely to have affected her ability to perform to her optimum during this assessment, and she was cooperative and pleasant throughout, with evidence of consideration of materials used, and some self-correcting as appropriate.

The WAIS-IV provides information regarding four indices of ability and provides an overall full-scale IQ score. There were no unusual differences between the subtests or indices.

- The **Verbal Comprehension Index (VCI)** measures acquired knowledge and verbal reasoning through three core subtests. Rose achieved a VCI score in the extremely low range (1<sup>st</sup> percentile<sup>17</sup>, 95% confidence interval 59-70). All her subtests were performed at the same level.

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<sup>16</sup> The WAIS-IV is an individually administered test of intellectual level for adults aged 16 through 89. It is made up of ten core subtests and five optional subtests, each assessing a person's ability to perform a different task of intellectual functioning. Performance is reported as index scores and a Full-Scale Intelligence Quotient (IQ). The FSIQ score is a summary of intellectual functioning, where a person's IQ is compared to a large sample of others in the same age range. Intellectual disability is indicated when a person's FSIQ is below 70 (with some flexibility for standard error of measurement). The index scores are the Verbal Comprehension Index, which measures acquired knowledge and verbal reasoning through three core subtests; the Perceptual Reasoning Index is a non-verbal measure of fluid reasoning, attentiveness to detail, and visual-motor integration through three core subtests; the Working Memory Index requires the examinee to attend to information, to hold briefly and process that information in memory, and then to formulate a response through two core subtests; and the Processing Speed Index is a measure of the individual's ability to process visual information quickly through two core subtests. Caution should be taken when generalising results to a New Zealand population as this measure was standardised in the USA.

<sup>17</sup> Each test score is stated in this report in the form of a *95% confidence interval* or, in other words, a range within which we can be 95% certain that the true score falls within. This range mathematically accounts for the margin of measurement error that is inherent in the particular test used. The reporting of scores in this 95% confidence interval is in accordance with standard clinical practice and also consistent with guidelines provided by the Ministry of Health.

- The **Perceptual Reasoning Index** (PRI) is a non-verbal measure of fluid reasoning, attentiveness to detail, and visual-motor integration through three core subtests. Rose achieved a PRI score in the extremely low range (1<sup>st</sup> percentile, 95% confidence interval 59-71). The subtests again showed little variation.
- The **Working Memory Index** (WMI) requires the examinee to attend to information, to hold briefly and process that information in memory, and then to formulate a response through two core subtests. Rose achieved a WMI score in the extremely low range (0.4 percentile, 95% confidence interval 56-69).
- The **Processing Speed Index** (PSI) is a measure of the individual's ability to process visual information quickly through two core subtests. Rose achieved a PSI in the extremely low range (0.3 percentile, 95% confidence interval 55-71).
- Rose's **Full-Scale IQ** (FSIQ) was in the extremely low range (0.1 percentile, 95% confidence interval 52-60).

Rose had her adaptive functioning assessed using the **Adaptive Behavior Assessment System, Third Edition**<sup>18</sup> with her mother, Theresa Greene, as the informant. Her mother has lived with Rose throughout her life and has had extensive opportunities to observe her skills and abilities in many areas. Given this, she meets Harrison and Oakland's (2003) criteria to be a valid informant. The Work Skill area was not completed as Rose has not recently had any employment or other work.

The results of the ABAS indicated that five of the nine skill areas were assessed in the extremely low range (Functional Academics, Leisure, Community Use, Health and Safety, and Self-Care). Rose had three skill areas assessed as being in the borderline range (Communication, Self-Direction, and Social). She had one skill area assessed as being in the low average range (Home Living). Her Self-Care skills were rated as being significantly weaker than her overall skills, and that this weakness was found in only 10% of people and is therefore unusual. Her Home Living was regarded as a strength, the level of which is found in only 10% of people, therefore is considered unusual. Her Self-Direction was another strength, the level of which was found in 10-25% of people, therefore this may be unusual, given that any discrepancy found in 15% of the population or less is unusual (Sattler & Ryan, 2009<sup>19</sup>).

Rose's scores in the composites were all in the extremely low range. Her Conceptual composite score was rated at 2<sup>nd</sup> percentile, 95% confidence interval 65-73. Her Social composite score was rated at 2<sup>nd</sup> percentile, 95% confidence interval 64-76. Her Practical composite score was at the 1<sup>st</sup> percentile, 95% confidence interval 59-67. Her Conceptual and Practical composite skills were significantly different, but the magnitude of that difference was not unusual. Therefore, her Global Adaptive Composite is considered a reliable indication of her overall functioning. This was rated at the 0.4 percentile, 95% confidence interval 57-63.

## CONCLUSIONS AND RECOMMENDATIONS:

- Rose meets the first and second criteria required for the diagnosis of an intellectual disability. Information provided by Rose and her mother indicates that she has had difficulty learning and developing independent skills to the level expected of her age throughout her life. Therefore, she should be considered to also meet the third criterion for the diagnosis of an intellectual disability.
- Given that Rose does have a mild intellectual disability I recommend that she is offered appropriate further assessments, such as a Needs Assessment. Rose is most likely to require on-going support with managing finances, with self-care, areas of health and safety, and in developing skills for employment. She may also benefit support in developing a wider range of interests in leisure activities and being encouraged to participate in these.

*Lily White*

<sup>18</sup> The ABAS-3 provides a norm-referenced assessment of adaptive skills of children aged 5-21 years and adults aged 16-89 years. The purpose of the ABAS-3 is in the diagnostic assessment of individuals having difficulties with the daily skills necessary to function effectively in their environments, given the typical demands placed on individuals of the same age. The ABAS-3 is a questionnaire covering ten adaptive skill areas and provides three composite scores, and one overall composite. Caution should be taken when generalising results to a New Zealand population as this measure was standardised in the USA.

Each test score is stated in this report in the form of a *95% confidence interval* or, in other words, a range within which we can be 95% certain that the true score falls within. This range mathematically accounts for the margin of measurement error that is inherent in the particular test used. The reporting of scores in this 95% confidence interval is in accordance with standard clinical practice and also consistent with guidelines provided by the Ministry of Health.

<sup>19</sup> Sattler, J.M. & Ryan, J.J. (2009) *Assessment with the WAIS-IV*, San Diego: Sattler.

**Lily White**

Registered Clinical Psychologist

MNZCCP, MNZPsS; M.A., PGDipClinPsych

***Note: The information in the following data is only to be viewed in conjunction with the psychological report dated 8 March 2022 and is only to be interpreted by a suitably registered Psychologist or Intern Psychologist.***

**APPENDIX – Wechsler Adult Intelligence Scale, Fourth Edition**

Index	95% Confidence Interval	Percentile Interpretation	Scale Subtest	Subtest Score
Verbal Comprehension Index	59-70	1 Extremely low	Similarities	4
			Vocabulary	3
			Information	4
Perceptual Reasoning Index	59-71	1 Extremely low	Block Design	3
			Matrix Reasoning	3
			Visual Puzzles	5
Working Memory Index	56-69	0.4 Extremely low	Digit Span	2
			Arithmetic	4
Processing Speed Index	55-71	0.3 Extremely low	Symbol Search	1
			Coding	4
<i>Full Scale IQ</i>	<i>52-60</i>	<i>0.1 Extremely low</i>		

**APPENDIX – Adaptive Behavior Assessment System, Third Edition**

Domain	95% Confidence Interval	Percentile Interpretation	Skill Area	Subtest Score
Conceptual Composite	65-73	2 Extremely low	Communication	5
			Functional Academics	2
			Self-Direction	6
Social Composite	64-76	2 Extremely low	Leisure	4
			Social	5
Practical Composite	59-67	1 Extremely low	Community Use	3
			Home Living	7
			Health & Safety	3
			Self-Care	1
			Work	-
<i>General Adaptive Composite</i>	<i>57-64</i>	<i>0.4 Extremely low</i>		

## **Appendix Four – Psychometric Reports: Test Briefs**

### **What is a Psychometric Test?**

The word psychometric is from the Greek words for mental and measurement. Psychometrics is the field of study concerned with the theory and technique of psychological measurement. This includes the measurement of knowledge, abilities, attitudes, personality traits, and educational measurement. The function of psychological tests is to measure differences between individuals or between the reactions of the same individual under different circumstances. Psychometric tests should not be used in isolation: they represent just one of the methods used by clinicians to make decisions about diagnosis or treatment pathways. Psychologists should choose appropriate comprehensive psychometric tests to complete their assessment and data should remain secure. Any online assessment system used should meet rigorous security protocols. In relation to intellectual disability there are two main forms of tests used to describe aptitude and ability; these are tests of cognitive ability and measures of adaptive functioning. The following is not a list of approved tests; each clinician who performs an evaluation needs to use his/her own judgment as to what is the most appropriate test for each particular client. Caution should be taken when generalising results of any test standardised in another country to a New Zealand population.

### **Tests of Cognitive Functioning (Intelligence tests)**

Intelligence tests come in many forms, including measures of single or multiple aspects of a person's ability. Regardless of design, all IQ tests attempt to measure general intelligence and most provide an overall IQ score or estimate. An IQ can be reported as a single score when all those elements that make it up are performed at a similar level. If there is significant variation within the IQ score, it may not be able to be validly calculated. IQs should be reported with a 95% confidence interval – the range within which the true score is likely to fall. The IQ score is a snapshot assessment of how the person performed on that day. There are many situational factors that are required for an achieved IQ score to represent how a person usually functions and these include effort, mental state, physical state, physical environment, personal background, and assessor skills.

As at date of publication of these guidelines, these are the most recent versions of the tests. These are likely to be updated during the lifetime of these guidelines and it is important for psychologists to remain mindful of any updated versions.

### **Comprehensive Assessments**

#### **The Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV)**

The WAIS-IV is an individually administered test of intellectual functioning for adults aged 16 through 89. It is made up of ten core subtests and five optional subtests, each assessing a person's ability to perform a different task of intellectual functioning. Performance is reported as index scores and a Full-Scale Intelligence Quotient (FSIQ). The FSIQ score is a summary of intellectual functioning, where a person's ability is compared to a large sample of others in the same age range. The index scores are the Verbal Comprehension Index, which measures acquired knowledge and verbal reasoning; the Perceptual Reasoning Index, which is a non-verbal measure of fluid reasoning, attentiveness to detail, and visual-motor integration; the Working Memory Index, which requires the examinee to attend to information, to hold briefly and process that information in memory, and then to formulate a response; and the Processing Speed Index, which is a measure of the individual's ability to process visual information quickly.

#### **The Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V)**

The WISC-V is an individually administered intelligence test for children between the ages of 6 and 16 (inclusive). The WISC-V includes five composite scores and generates a Full-Scale IQ (FSIQ) that represents overall cognitive ability. The composite scores are the Verbal Comprehension Index, which measures acquired knowledge and verbal reasoning; the Visual Spatial Index, which tests the ability to understand visual spatial relationships in order to construct geometric designs; the Fluid Reasoning Index which measures the ability to detect underlying conceptual relationships among visual objects and use reasoning to identify and apply rules, the Working Memory Index, which requires the examinee to attend to information, to hold briefly and process that information in memory, and then to formulate a response; and the Processing Speed Index, which is a measure of the individual's ability to process visual information quickly.

#### **The Stanford-Binet Intelligence Scales, Fifth Edition (SB5)**

The SB5 is a standardised test that measures intelligence and cognitive abilities in people from age two through to 90 years. It is made up of 10 subtests, five verbal and five non-verbal, each assessing a person's ability to perform a different task of intellectual functioning. The Full-Scale IQ (FSIQ) is an aggregate of Nonverbal and Verbal IQ and is used to calculate the intellectual level of the person being tested. In addition to overall IQ scores, five broad ability factors are also measured. These are: Fluid reasoning, the ability to solve verbal and nonverbal problems using inductive or deductive reasoning; Knowledge, a person's accumulated fund of general information acquired at home, school, or work; Quantitative reasoning, an individual's facility with numbers and numerical problem solving, whether with word problems or pictured relationships; Visual-spatial processing, an individual's ability to see patterns, relationships, spatial orientations, or the gestalt whole among diverse pieces of a visual

display and Working Memory; a class of memory processes in which diverse information stored in short-term memory is inspected, sorted, or transformed.

## **Nonverbal Assessments**

### **Universal Nonverbal Intelligence Test 2 (UNIT™ 2)**

The UNIT-2 Provides a multidimensional assessment of intelligence for children aged 5 years to young adults aged 21 years 11 months in a completely nonverbal format. It is based on a national sample of 1,800 individuals from 33 states of the USA. It provides seven composite scores—Memory, Reasoning, Quantitative, Abbreviated Battery, Standard Battery with Memory, Standard Battery without Memory, Full Scale Battery through individually administered nonverbal tasks.

### **Comprehensive Test of Nonverbal Intelligence | Second Edition (CTONI-2)**

The CTONI-2 is a norm-referenced test using nonverbal formats. It measures general intelligence of children and adults who might be adversely affected by subtle or overt impairments involving language or motor abilities. It provides information about nonverbal Measures analogical reasoning, categorical classification, and sequential reasoning.

### **The Test of Nonverbal Intelligence, Fourth Edition (TONI-4)**

The TONI-4 is a test of cognitive ability using nonverbal formats and pointing responses to measure general intelligence. It is an ideal test for those who have significant language, hearing or motor impairments, or those who are not familiar with mainstream American culture. It has two equivalent 60 item forms arranged in easy to difficult order, normed for use with examinees ranging in age from 6 years through to 90 years.

### **The Raven's Progressive Matrices, Second Edition (Raven's 2)**

The Raven's 2 is a nonverbal test that screens cognitive ability by requiring the examinee to solve visual problems presented in abstract figures and designs. The standard version has relatively recent norms (published in 2018). The tests can be used from five years up to the adult level. They are most helpful for people who have a significant language impairment (e.g., are nonverbal) or come from a minority cultural background where there may be a need to use a test that is less culturally biased.

## **Other Assessments**

### **The Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II)**

The WASI–II, provides a brief, reliable screen of cognitive ability of people aged 6 years to 90 years 11 months for use in clinical, educational, and research settings. This can be used when screening for intellectual disabilities or intellectual giftedness, or to screen to determine if in-depth intellectual assessment is needed and it provides an estimated range of FSIQ scores.

### **The Peabody Picture Vocabulary Test, Fifth Edition (PPVT-5)**

The PPVT-5 is a test of receptive vocabulary for American English. The PPVT-5 provides an estimate of a person's verbal intelligence, and can be particularly useful for people who have expressive language difficulties as it does not require any verbal responses. The PPVT-5 can also be used for assessing the English vocabulary of non-English-speaking individuals and assessing child and adult verbal ability.

### **The Expressive Vocabulary Test, Third Edition (EVT-3)**

The EVT-3 is an individually administered norm referenced instrument that assesses expressive vocabulary and word retrieval for children and adults aged 2 years 6 months through 90 years and older. It measures expressive vocabulary knowledge with two types of items, labelling and synonym.



## **Measures of Adaptive Functioning**

Measures of adaptive behaviour evaluate a person's ability to cope with the demands of their environment. Adaptive behaviour is age-related and becomes more complex as a person grows older. Adaptive behaviour measures focus on what the person is capable of doing on a typical day rather than trying to measure their "ability" to learn. The main cautionary note regarding adaptive behaviour instruments is that they are generally reliant upon the report of parents, teachers, or other caregivers. These ratings can range from being highly valid in many cases, to being invalid or fairly misleading in other cases. The person responsible for administering the adaptive behaviour assessment should try to determine the validity of the information that is gathered.

### **The Vineland Behaviour Scales, Third Edition (Vineland-3)**

The Vineland-3 has an age range that goes from birth to 90 years. It samples communication, daily living skills, socialisation, motor skills, and maladaptive behaviours. The Vineland-3 utilises three different formats, a semi-structured interview format, a Parent/Caregiver Rating Form, and a Teacher Rating form.

### **The Adaptive Behaviour Assessment Schedule, Third Edition (ABAS-3)**

The ABAS-3 provides a norm-referenced assessment of adaptive skills of people aged 5-89 years. The ABAS-3 covers ten adaptive skill areas and provides three composite scores, and one overall composite. Norms are available for parent and teacher reports for children, and self-report and other report for adults.

### **The Scales of Independent Behaviour - Revised (SIB-R)**

The SIB-R provides a comprehensive assessment of 14 areas of adaptive behaviour and eight areas of problem behaviour. The age norms run from infancy to 80+ years. There is a full-scale form, a short form and an early development form. The full-scale form samples motor skills, social interaction and communication skills, personal living skills, and community living skills. The short form is a brief overall screening or evaluation tool that contains a total of 40 items from the 14 subscales in the total scale. The early development form contains 40 items sampled from developmental areas of the full-scale that are particularly suitable for assessing the development of pre-schoolers and of youth or adults with severe disabilities.

## **Tests of Effort (Performance Validity)**

Cognitive assessment is fundamentally reliant on a person's meaningful participation in the testing process. Clinicians consistently overestimate their ability to subjectively gauge effort and underestimate the frequency with which participants do not apply effort. For these reasons, effort testing must be used to ascertain the validity of test results in all assessments. Specific effort tests should not be named in the report to maintain the integrity and utility of the tests.

### **The Medical Symptom Validity TEST (MSVT)**

This is an easy to administer, computer-based test of verbal memory that contains an embedded effort test. It contains two primary effort subtests and two memory subtests. The MSVT is sensitive to poor effort and insensitive to all but the most extreme forms of cognitive impairment (and therefore can be used with people suspected of intellectual disability).

### **The Test of Memory Malinger (TOMM)**

The TOMM is a test of visual recognition designed to help discriminate between simulated and true memory impairments. Participants are shown a series of images before having to choose between images that were previously presented and images that were not.

## ***Appendix Five – Schedule 4 Code of Conduct for being an Expert Witness***

### **Expert evidence, Schedule 4**

(Appendix and explanation – refer to R v Hutton 2008, NZCA 126)

- An expert is someone who has specialised knowledge and skill; evidence is admissible in Court if it is likely to provide substantial help to the Court (ss4 and 25 Evidence Act 2006; also defined in r1.3 of the High Court Rules). The Code of Conduct for Expert Witnesses states in rule 9.43 that the person has a duty to comply with Code in Schedule 4 to the High Court Rules (which also apply in the District Court).
- An expert has an overriding duty to assist the court impartially on relevant matters within the expert's area of expertise. An expert witness is not an advocate for the party who engages the witness.
- If an expert witness believes that his or her evidence or any part of it may be incomplete or inaccurate without some qualification, that qualification must be stated in his or her evidence.
- If an expert witness believes that his or her opinion is not a concluded opinion because of insufficient research or data or for any other reason, this must be stated in his or her evidence).

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# PRACTICE NOTE: ASD DIAGNOSIS

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## **Purpose**

The purpose of this memo is to clarify the expected level of evidence provided to the NASCs and Ministry of Health when offering the diagnosis of ASD to support a referral to DSS.

## **Background**

People with ASD and no accompanying ID (ASD only) are eligible to receive support services from DSS. The Ministry has issued guidelines (the Guidelines)<sup>1</sup> about the qualifications and experience of clinicians who are providing diagnosis of ASD.

The Guidelines recommend that a multidisciplinary team with ASD expertise contributes to the diagnostic decision and that the evidence gathering to support this diagnosis is structured around the diagnostic criteria, and is supported by using one of the recognised structured protocols, such as the ICD or DSM. Use of the protocols ensures that evidence for and against the diagnosis is considered, including differential diagnoses, and provides a clear basis for transparency about how the diagnosis was determined. The Guidelines also state; 'In the absence of an assessment team, a health care practitioner trained and highly experienced in ASD may undertake diagnostic assessment'. This would include paediatricians, psychiatrists and clinical psychologists.

In most cases the diagnosis is clear and with the information provided by Child Development Services, Paediatric Outpatients, Child and Adult Mental Health Services and NASC assessments, eligibility for support services and an intervention plan can be agreed locally. The Ministry supports the NASCs in deciding whether to accept a referral where ASD only is the diagnosis (when eligibility is unclear or when agreement cannot be reached locally) by convening the ASD Escalation Panel (the Panel). The Panel is responsible for decisions around eligibility for people with ASD and complex presentations or who may require high cost packages of care. The Panel comprises representatives from both DSS and Mental Health.

The Guidelines established the principle that support packages should maximise independence and those people in transition to independence should be supported to achieve this. Most people with ASD and no ID can live independently although some may require support to do so. Clinical rigour is required around diagnosis and formulation to ensure intervention does not engender dependence with long term personal and fiscal consequences.

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<sup>1</sup> New Zealand Autism Spectrum Disorder Guideline (2008) is available at <http://www.moh.govt.nz>

The Panel has been asked to clarify the level of detail required in the referral to the NASC and the supporting evidence that may need to be presented to the Panel. This memo sets out these expectations for clinicians and referring agencies. It is not intended to call into question the clinician's ability to diagnose ASD. Clarity of diagnostic information will allow timely decisions to be made about eligibility for service and level of service that may be required.

### **Diagnostic requirements**

Clinicians are expected to be familiar with the Guidelines and to apply these to their practice where DSS funding is sought. This includes gathering relevant history and diagnostic evidence in a systematic way, applying this evidence to the diagnostic criteria and arriving at a diagnostic conclusion having considered all the evidence. The logic of this decision should be set out in such a way that it is transparent to the Panel and this includes alternative diagnoses that were eliminated or found to be comorbid during the decision making process.

If required by the Panel, the evidence for the diagnosis must be able to be presented and this will include structured decision making processes and case notes<sup>2</sup>. The Panel will typically ask for this information where the diagnosis is unclear or there may be other possible diagnoses that may impact on the configuration of support required. In these situations diagnostic information may also be used in discussions with other possible support agencies such as the Mental Health services.

### **Action required**

When referring, please provide the following brief information to the NASC:

1. the diagnostician's clinical rationale for the ASD diagnosis based on the diagnostic criteria with supporting evidence
2. a brief summary of the assessment process undertaken
3. an indication of likely disability related support needs
4. a list of coexisting mental or physical health diagnoses, as well as current or planned treatment.

Please ensure all teams and clinicians who may refer these cases to the NASC are informed of these requirements. Questions can be directed to the NASC.

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<sup>2</sup> This should include provision of MH assessment reports (with information not relevant to the diagnostic decision or intervention plan redacted if necessary) or a comprehensive summary that clearly sets out the relevant history and diagnostic process.

## **Excerpt from Operational Manual for Needs Assessment and Service Co ordination Managers**

### **Volume 1 – Ministry of Health (May 2005)**

#### **Who Can Access Ministry-funded Disability Support Services?**

NASC should ensure services are provided only to those disabled people who are eligible to receive them, as required by the Guide to Eligibility for Publicly Funded Health and Disability Services in New Zealand (see Ministry website [www.moh.govt.nz](http://www.moh.govt.nz)) and DSD NASC Service Specification (see Volume 2, Appendix 1).

The Government's definition of disability [CAB (94) M 3/5(1a) refers] determines who is eligible for Ministry-funded DSS via a NASC. The definition states that:

*A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory, or age-related disability (or a combination of these), which is likely to continue for a minimum of six months and result in the reduction of independent function to the extent that ongoing support is required.*

In applying the definition, the Ministry will fund a range of DSS for people who have been assessed as having a physical, intellectual or sensory disability (or a combination of these). Clients with these disabilities constitute the Ministry's main client group given that DSS funding for people with psychiatric disability and age-related disability has been devolved to DHBs.

The Ministry will also fund DSS for people with certain neurological conditions that result in permanent disabilities, certain developmental disabilities in children and young people, and physical, intellectual or sensory disability that co-exists with a health condition and/or injury. A NASC can clarify these by contacting its DSD Service Manager.

#### **Who is Excluded from Ministry-funded Disability Support Services?**

In principle, no person is excluded from accessing Ministry-funded DSS if they are assessed as having a disability-related need under the Government's definition of disability and if their needs can be met within the existing range of services. The latter criterion means having a disability or clinical diagnosis is itself not an automatic entitlement to accessing Ministry-funded DSS. For example, some people with a mild disability may not require Ministry-funded supports.

The Ministry will not fund DSS for people whose primary needs are driven by acute or chronic health conditions, mental health, health conditions more commonly associated with ageing, or injury or accident. The Ministry expects that support services for these people will be funded by DHBs and ACC (Injury, Prevention, Rehabilitation and Compensation Act 2001) respectively.

In summary, the following client groups are generally ineligible for Ministry-funded DSS:

mental health and addiction conditions including dementias, attention deficit disorders  
acute and chronic health conditions including epilepsy and morbid obesity

palliative care conditions

conditions more commonly associated with ageing including 'close in interest' (see below)

injury or accident resulting in permanent disabilities (since 1974).

The Ministry of Health does not provide DSS when a client's needs might reasonably be met from another service area or where there is no existing service in that area for meeting the client's needs.

## How is Eligibility Determined?

Determining eligibility for disability support services will involve some or all of the following processes.

Ministry-funded NASCs should have protocols in place with their funding agencies to support **decision-making** on eligibility as required (see Pathway for accessing Ministry-funded DSS below). A NASC should contact its DSD Service Manager if there is any doubt about a person's eligibility.

Ministry-funded NASCs should have a standard procedure for screening **referrals** and a clear communication process for responding to referrals that are ineligible for NASC services. All referrals should be screened to establish/confirm eligibility for DSS before commencing needs assessment. This may require some investigation of the nature and extent of disability. Referrals should be rejected at either initial screening, or subsequent facilitated needs assessment, if screening indicates clearly that the person's needs should not be met within Ministry-funded DSS.

A facilitated **needs assessment** may be required to help establish eligibility for DSS as well as determine support need. This may require a referral between service areas for a specialist functional assessment or other clinical assessment. A specialist assessment may also be required to determine eligibility and access to environmental support services (ESS).

A **diagnosis** may be required to help determine eligibility. Some conditions such as autism will require a diagnosis to enable the client to access Ministry-funded DSS.

## Close in Interest Protocols

Ministry-funded NASCs should follow any local protocols developed to manage referrals for clients who require DHB clinical assessment as close in interest to persons aged 65 and over and who require access to DSS.

## **Shared Funding Arrangements**

Clients with co-existing health and disability needs may require services from different funders such as the Ministry, DHBs and ACC. Ministry-funded NASCs should discuss with their DSD Service Manager the need for any formal agreement with other funders on the relative funding responsibilities to address co-existing needs.

## **Boundary management**

Ministry-funded NASCs should not provide DSS to clients whose support needs should be met by other service areas. Health referrals should not be accepted until a clear position is reached on eligibility of the person concerned. This is to save on unnecessary facilitated needs assessments and ensure clients are not wrongly accepted for Ministry-funded DSS. Boundary cases should be investigated carefully to determine whether they fit with the DSS framework or elsewhere. Compelling clinical and case history evidence will therefore be required to indicate presence of disability or disability-related need under the definition of disability and for a needs assessment to be undertaken to confirm eligibility.

## **Transfer of Clients from Ministry-funded DSS**

Existing Ministry-funded clients who are subsequently found to be ineligible for Ministry-funded services should not have their services terminated until a transfer/exit process has been established with the client and the appropriate service area.

In 2005 the Ministry will be working with NASCs and DHBs to identify a transfer process and ensure that it occurs. In the interim, NASCs should continue any existing services to clients in order to protect the client's interests while transfer issues are being resolved.

## **Dispute Resolution**

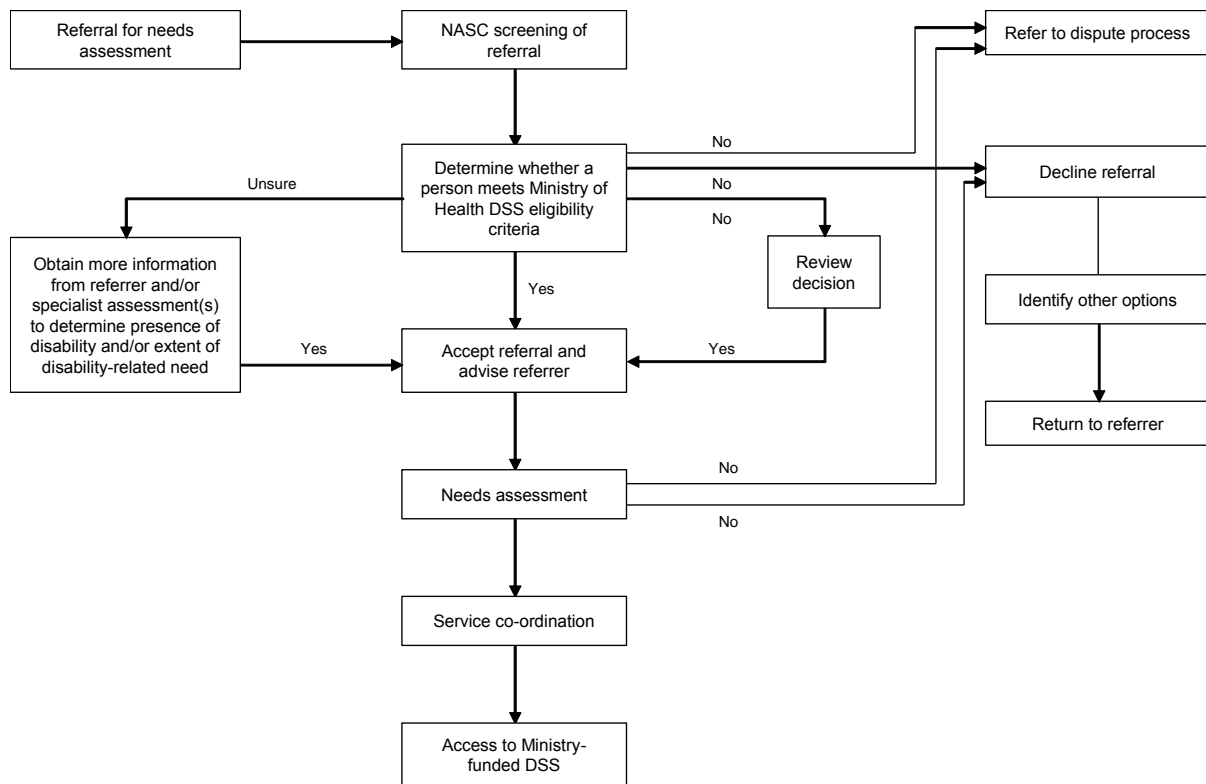
Services to disabled people should be continued while boundary issues are being resolved. Any disagreement between services over the funding stream to which the disabled person is allocated should be resolved at the lowest level of management, by informal means first, as far as possible. This means that in the first instance, boundary issues should be resolved between a Ministry-funded NASC and DHB-funded NASC or health service or other referring agency. Where the NASC cannot reach agreement with the referring agency, the issue should be escalated to the Ministry's DSD Service Manager or Northern or Southern Operational Team Manager and to the DHB (Planning and Funding Manager) or ACC or other agency.

In 2005 the Ministry of Health will work with NASCs on developing dispute resolution processes to help NASCs manage the more/most difficult boundary issues with DHB-funded older people's services, personal health, mental health services and other services where agreement cannot be reached on which agency is responsible for the client's support needs.



## Pathway for Accessing Ministry-funded DSS

The flow chart shows the process that NASCs use to determine eligibility for Ministry-funded DSS. Access to Ministry-funded ESS is via a separate assessment process.



## Eligibility Assessment Guidelines for People with an Intellectual Disability

The *Intellectual Disability Eligibility Assessment: Guidelines for Requests and Reports* (Ministry of Health 2003) have been developed to establish a collaborative effort between NASC organisations and psychologists working in the area of intellectual disability.

The purpose of this document is to establish accurate and consistent practice in assessing intellectual disability for the purposes of establishing eligibility to receive services specifically targeted by Ministry of Health intellectual disability service contracts. National clinical representation has been sought and both national and international standards used in relation to these Guidelines.

An Eligibility Assessment is the formal evaluation undertaken by a psychologist or other suitably qualified professional to establish if a person has an intellectual disability. This process is undertaken in order to establish eligibility for services specifically contracted by the Ministry of Health for people with intellectual disabilities and NASC disability services in general.

## **Resource**

Volume 2 Appendices

Appendix 4: Ministry of Health. June 2003. *Intellectual Disability Eligibility Assessment: Guidelines for Requests and Reports.*

## **Excerpt from Operational Manual for Needs Assessment and Service Co ordination Managers - Appendices**

### **Volume 2 – Ministry of Health (May 2005)**

## **3 SERVICE USERS**

### **3.1 Inclusions**

People eligible according to the *Guide to Eligibility for Publicly Funded Health and Disability Services in New Zealand* who have been assessed as having a physical, intellectual or sensory disability (or combination of these) that is likely to continue for a minimum of six months; result in reduction of independent function; and require ongoing support.<sup>1</sup> People with these disabilities constitute the Ministry's main client group, which largely consists of people aged under 65, many of whom have lifelong impairments.

People with physical, intellectual or sensory disability that co-exists with a personal health condition, mental health condition and/or injury, in relation to their disability support needs.

The NASC will consult with the Ministry for prior agreement in relation to people under 65 whose needs may have historically been recognised as disability-related within the parameters of the definition of disability.

### **3.2 Exclusions**

People who are covered under the Injury, Prevention, Rehabilitation and Compensation Act 2001. ACC has been responsible since 1974 for funding support services for people whose disability is caused by injury or accident.<sup>2</sup>

People aged 65 years and over who do not have a long term impairment (ie, physical, sensory, intellectual or cognitive disability that was acquired before the age of 65 years)

People aged 65 years and over with a long term impairment who have been Ministry funded but who have been clinically assessed by a DHB or needs assessor as requiring age related residential care.

People aged 50–64 years who have been assessed by a DHB or DHB needs assessor as 'close in interest' to persons aged 65 years and over and whose needs would be best met by DHB integrated health and disability services.

People who require an assessment solely as a result of a mental health need or addiction condition – these assessments are contracted for by the DHB through Mental Health Assessment Services or Community Mental Health teams.

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<sup>1</sup> Although people with psychiatric disability and 'age-related' disability with support needs can be assessed for access to support services they are excluded from the Ministry's operation of the definition.

<sup>2</sup> Injury, Prevention, Rehabilitation and Compensation Act 2001 refers.

People who require assessment as a result of a personal health need. A personal health need is defined as when a person's level of independent function is reduced by a condition that requires ongoing supervision by a health professional.

### **3.3 Interface with NASC for people 65 years and over**

The NASC will maintain working relationships and agreed protocols with DHB NASC working with older people.

### **3.4 Interface with Mental Health**

For those people with a dual diagnosis, that being a co-existing mental illness and disability, the NASC will work in collaboration with the relevant Mental Health Service.

### **3.5 Interface with Personal Health**

Following an acute illness and the completion of post-discharge care and treatment, a disabled person can be referred to a NASC for their disability support needs.

### **3.6 Interface with Other Agencies**

Depending on the needs of the person it may be appropriate for the NASC to jointly facilitate needs assessment with other appropriate agencies.