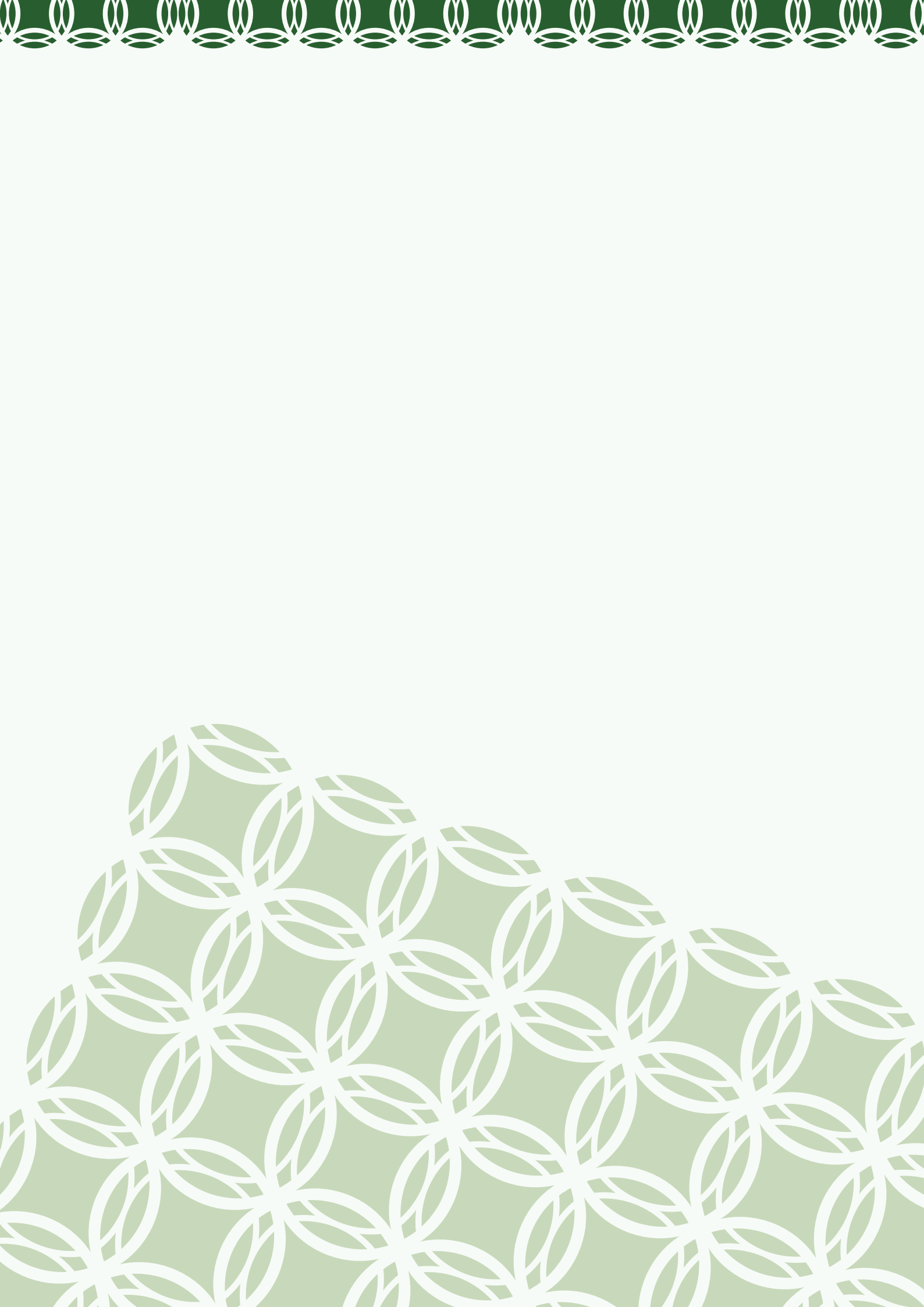
Provider care recordkeeping guidance

Disability Support Services

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA



Contents

1 Summary of recordkeeping guidance for providers of disability support services

1.1 Purpose of the guidance

The guidance and its supporting resources are intended to help disability support service providers to better understand their care recordkeeping obligations and improve their practices.

1.2 What are care records?

These are the pieces of information that an organisation creates or records about a person while responsible for providing them with care or support.

Archives New Zealand defined care records by asking people which records were the most valuable to them and most needed protection.

1.3 Why are they important?

Care records are taonga for the person the records are about. They can hold memories, connections, and explain important decisions that were made about the person.

When created, looked after, and provided in a person-centred way, these records can provide meaningful answers for questions in people's lives.

1.4 Which recordkeeping issues did people share with the Royal Commission of Inquiry?

Among other issues, people have described the impact of receiving records with offensive wording, big information gaps, and without any of their own views or voice reflected in them.

The process of accessing care records was often described as confusing, slow, and demoralising. When people did receive their records, there could be lots of information blacked out and difficult information they didn't expect to receive.

1.5 Which areas of recordkeeping practice does the guidance address?

The guidance focuses on the key practice areas of creating, managing and providing access to care records.

As these practices all play a role in helping to answer people's questions, they are all important to get right.

The guidance explains how providers can meet their legal obligations and make other improvements in each area.

1.6 What are some legal obligations that providers have when working with care records?

Providers must:

- create full and accurate records of the services they are providing
- store people's personal information securely and protect it against loss, damage, or destruction for as long as is necessary
- ensure that people's personal information is accessible to them and respond to requests for access within the required timeframe and without unreasonable delay.

1.7 What are some other things that providers can do to improve people's experiences?

Providers should:

- create care records alongside disabled people using respectful, clear, and understandable language and keeping their autonomy in mind
- store and look after care records in a way which keeps them safe, is respectful, and allows access to be as quick and easy as possible
- handle access requests with empathy, provide people with options wherever possible, and communicate proactively.

Quick reference guide

for staff creating care records

2 Quick reference guide for staff creating care records

2.1 The records you create are important

Remember that the records you create are taonga for the person the records are about. They can hold sensitive information, memories, connections and explain important decisions made about the person.

When created in a person-centred way, these records can provide meaningful answers for the questions in people's lives.

2.2 You have obligations when creating records

You must create full and accurate records of the services that you are providing.

2.3 The way you create records can make a difference for people

You can make a difference by creating records alongside disabled people using respectful, clear, and understandable language and keeping their autonomy in mind.

2.4 There are some guiding principles you can follow when creating records

Create records with the disabled person where appropriate, reflecting their voice and needs

What good practice could look like when following this principle

- Make the disabled person aware that records are being created about them, and give them the opportunity to ask questions about, or contribute to, these records.
- Sit alongside the disabled person when creating records about a key decision, explain what is being recorded in a way that makes sense for them, ask for their views, and record their views in their own words.

- Explore different communication methods and options that enable the disabled person to contribute to their records on their own terms, in ways that are meaningful and appropriate for them.

Create accurate records which include different voices and perspectives where appropriate, and reflect the disabled person's whole support journey

What good practice could look like when following this principle

- Create records which include the positive aspects of a person's support journey. This could include positive comments from those providing support, or any other information to help give the person a balanced, accurate picture of their work with disability support service providers.
- Create full and accurate records about all incidents, responses and decisions affecting the safety and wellbeing of the people you are supporting and do this at, or as close as possible to, the time these events occur.
- Ensure that detailed records are created around the transition points of a person's support journey including the reasons for the transition, their views on the change and the support provided during these periods.
- Where you have the disabled person's permission and it is appropriate, help their support network to understand why key decisions are being made and record how the disabled person and the important people in their lives feel about these decisions.

Create records for the disabled person with an awareness of their enduring value to the person and their whānau, hapū, iwi and community

What good practice could look like when following this principle

- Create records with an awareness of the key role they can play in helping the disabled person to connect with their identity and whakapapa. Creating a record based on conversations with the disabled person about their relationships with their whānau and wider community can help to accurately capture their cultural identity.

- Create care records which capture the perspectives of the community around the person when key decisions are made about their support.
- Record and capture ethnicity, iwi and other community identifiers consistently to allow for anonymous reporting and enable a better understanding of the demographics of those receiving disability support services.

See more detailed guidance on creating care records

Quick reference guide

for staff managing care records

3 Quick reference guide for staff managing care records

3.1 The records you manage are important

Remember that the records you manage are taonga for the person the records are about. They can hold sensitive information, memories, and connections and explain important decisions made about the person.

When managed in a person-centred way, these records can provide meaningful answers for the questions in people's lives.

3.2 You have obligations when managing records

You must store people's personal information securely and protect it against loss, damage, or destruction for as long as is necessary.

3.3 The way you manage records can make a difference for people

You can make a difference by storing and looking after care records in a way which keeps them safe, is respectful, and allows lawful access to be as quick and easy as possible.

3.4 There are some guiding principles you can follow when managing records

Store and look after care records in a way which keeps them safe, is respectful, and allows access to be as quick and easy as possible

What good practice could look like when following this principle

- Store physical records with appropriate protections by ensuring that storage is fire safe, mould free, not in a location with a flood risk, and not leaving records in spaces where they are likely to be handled or read by people where it is not required for their work.
- Store digital records in alignment with Archives NZ's best practice guidance on digital storage and preservation - Best practice guidance on digital storage and preservation – Archives New Zealand

- Ensure that historical records are accessible throughout their retention period and keep a clear record of where to locate records to enable timely and thorough searches to locate information when people make requests.
- Before transferring or disclosing a disabled person's personal information to another provider, ensure that your organisation considers the following:
    - Was the disclosure of this information one of the purposes for which the information was originally obtained?
    - Am I disclosing only the minimum amount of information necessary?
    - Has the disabled person or their representative given their permission for this information to be disclosed?
    - Do any other exceptions to Rule 11 of the Health Information Privacy Code apply which enable or require me to disclose the disabled person's information?
    - Whether any of the information requested is out of scope?
- Be transparent if you've lost or destroyed someone's records. Encourage staff to locate the missing records where possible and to proactively make people aware of what has happened to their records.

Look for opportunities to identify the care records most valuable to people's identities in description and digitisation processes, including those of value to their whānau, hapū, iwi, and community

What good practice could look like when following this principle

- Consider the types of records likely to be of the most value to disabled people who request their care records. For example, birth certificates, medical documentation, letters from whānau members, support care plans or other documents detailing the key decisions or transition points in the disabled person's support journey.
- Consider which records might be the most valuable in the context of the specific services provided by your organisation.
- Review your organisation's current description and digitisation or metadata processes to look for possible opportunities to identify these most valuable records and make their presence and location visible.

Consider the enduring value of care records to people and their whānau, hapū, iwi and community in any decisions about their use, retention, transferral, or disposal and look for opportunities to involve them in these decisions

What good practice could look like when following this principle

- Build an organisational understanding of the scope and definition of care records using the care records definition published by Archives NZ and consider which records created and held by your organisation fit within this definition.
- Protect the care records that your organisation is responsible for in alignment with the Temporary care records protection instruction issued by NZ's Chief Archivist to prevent destruction of care records until Archives NZ completes its review of public office disposal authorities.
- When deciding how care records are used, retained, transferred, or disposed of; consider the value of these records to the people they are about and whether there is an opportunity to involve them in the decision. This could be by letting them know the reasoning behind a decision or giving them alternative options such as receiving their own copy of information.

See more detailed guidance on managing care records

Quick reference guide

for staff providing access to care records

4 Quick reference guide for staff providing access to care records

4.1 The records you help people to access are important

Remember that the records you provide access to are taonga for the person the records are about. They can hold sensitive information, memories, connections and explain important decisions made about the person.

When access is provided in a person-centred way, these records can provide meaningful answers for the questions in people's lives.

4.2 You have obligations when providing access to records

You must ensure that people's personal information is accessible and available to them and respond to requests for access within the required timeframe and without unreasonable delay.

4.3 The way you provide access to records can make a difference for people

You can make a difference by handling access requests with empathy, providing people with options wherever possible and communicating proactively.

4.4 There are some guiding principles you can follow when providing access to records

Empower people to make informed choices about how they engage through the access process and receive their care records

What good practice could look like when following this principle

- Provide different options for how requesters can contact your organisation and how they make their request. For example, a form can be a useful way to set out the information needed to request records; consider if requiring all requesters to fill it out would be an unnecessary barrier to access.

- Engage with people to understand which information they want and what's important to them. Adapt your response to meet what they've asked for, rather than taking a one-size-fits-all approach.
- Give the requester options on how (and how often) they want to communicate with your organisation throughout the process.
- Provide options for the requester around how they want to receive their records and engage with them to understand and try to enable their preferences.

Be transparent about how long it could take to provide people's care records and help them understand why

What good practice could look like when following this principle

- Proactively explain the release process to the requester in appropriate detail, including the factors which may make a request take longer than they might expect.
- Respond as soon as possible after receiving the request (but within the required 20 working days) to confirm whether you will be able to provide the information requested, and if not to explain the reasons for refusal.
- Provide the requester with an estimated release timeframe which is reasonable in the circumstances of their individual request.
- Explain why this can only be an estimate and that you will update them if the expected timeframe changes.
- Notify the requestor if the release is likely to take longer than the initially estimated timeframe you shared. Explain the reasons for the delay at an appropriate level of detail and provide an updated estimated timeframe for the records to be provided.

Make each redaction decision on its own circumstances with consideration of the value of the information to the requester

What good practice could look like when following this principle

- Weigh up each decision to redact based on the individual circumstances of the requester's information rather than applying a blanket approach to types of information.
- Consider the value of the information as a potential piece of the disabled person's identity and life story when deciding whether it is necessary to redact the information to protect a third party's privacy.

- When a redaction is necessary, explain the legal grounds for the redaction and why the redaction decision was made, in a way that the disabled person can understand.

Provide people with the necessary context about care records to help them prepare to receive their information

What good practice could look like when following this principle

- Explain to the requester the usual types of documents and information included in care records and do this as early in the request process as is possible and appropriate.
- Explain what redaction means, why things might be redacted and the type of information that might be withheld, for example sensitive information about other people.
- Proactively notify the requester about information which might be difficult to receive. Consider offering to put warnings before these pieces of information so the requester can make the necessary support arrangements.
- Offer to connect the requester with available support services who can assist them throughout the process of receiving and engaging with their records.

See more detailed guidance on providing access to care records

Detailed provider care recordkeeping guidance

5 Detailed provider care recordkeeping guidance

This guidance is not intended to change the legal rules relating to care records. It does not create new legal rights or binding obligations on Disability Support Service providers.

Its aim is to support providers to learn from the experiences of the survivors who gave evidence before the Abuse in Care Royal Commission of Inquiry in relation to records and to provide a best practice guide for providers to consider when assessing their legal obligations relating to care records.

What are care records?

Care records are taonga for the person at the centre of them. They can hold memories, connections and explain important decisions that were made about the person.

In 2024, following consultation which included care experienced people and organisations holding records, Archives NZ published a definition of care records to help government and other organisations know which records are most valuable for those in care.

This broad definition of care records has been used in this guidance to capture the types and range of records made about a person's time in the care of or while receiving support from, a Disability Support Services (DSS) provider.

Care records include both formal planning documents and day-to-day documentation, such as:

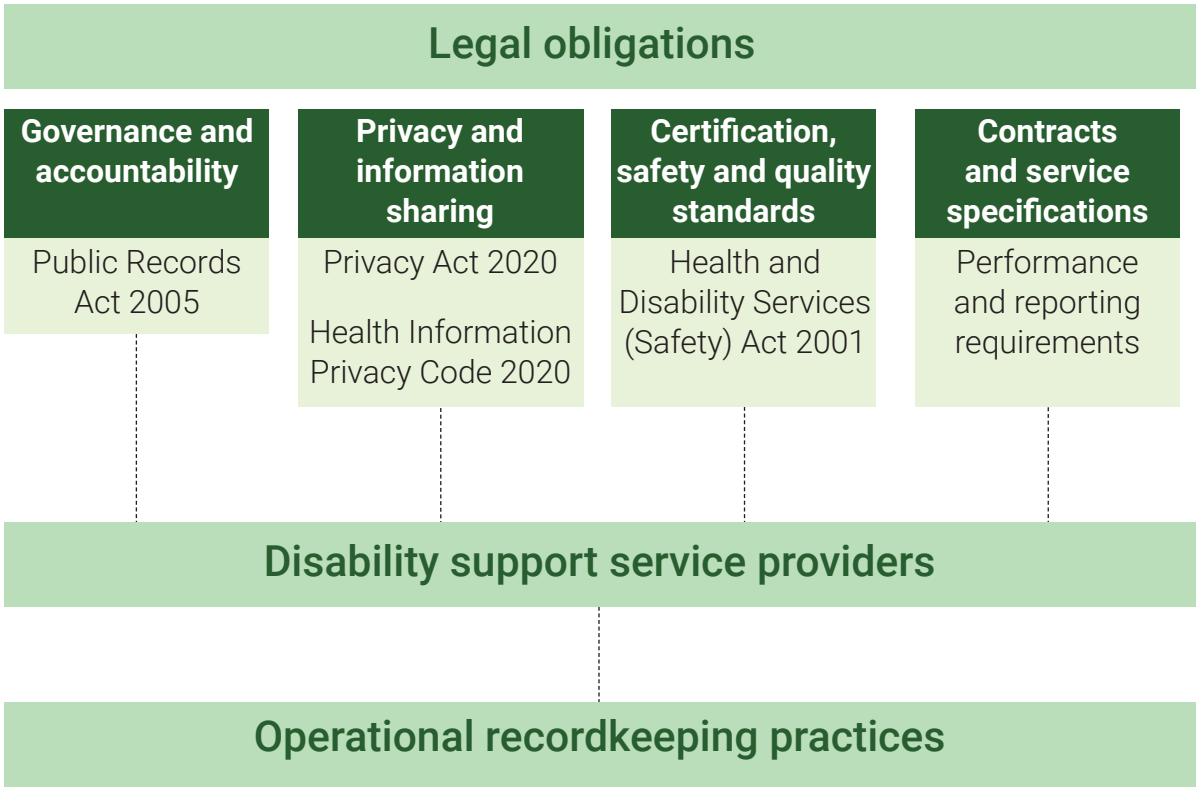
- My DSS Funding Plans, personal support plans, risk plans, behaviour support plans, health plans
- progress notes, case notes, assessments incident reports and emails about support provision.

Records may be in digital or paper formats, including legacy (not-current) materials stored offsite. Care records can also include photos, videos, and other artefacts.

You can find more information about the care records definition on Archives NZ's website through the link below.

The care records definition (archives.govt.nz)(external link)

Overview of recordkeeping obligations for disability support service providers



This diagram shows an overview of the different sources of recordkeeping related legal obligations providers have. These different sources are placed in boxes above a box saying Disability Support Service Providers with a box below showing how all of these obligations flow into the providers' operational recordkeeping practices.

5.1 Creating care records

This section focuses on the practices around creating care records.

This practice area is important to get right as care records created in a person-centred way can provide meaningful answers for questions in people's lives.

5.1.1 Legal obligations when creating care records

Several pieces of legislation set legal requirements for how providers create care records.

The excerpts and links below provide an overview of some key legislation for providers to be aware of when creating records.

Privacy Act 2020

The Privacy Act is the foundation of personal information sharing in New Zealand. Every provider, no matter their size or service type, must comply with the Privacy Act. It applies to all personal information an organisation collects, uses, stores, or shares.

The Act sets out the Information Privacy Principles (IPPs), which govern the entire lifecycle of personal information.

https://www.legislation.govt.nz/act/public/2020/31/en/latest/#LMS23352

The most relevant Privacy Principles for providers to consider when creating care records are:

Information privacy principle 1 – Purpose of collection of personal information

Principle 1 states that organisations must only collect personal information if it is for a lawful purpose connected with their functions or activities, and the information is necessary for that purpose. This principle is about data (information) minimisation.

When asking people for their personal information, think carefully about why you are collecting it. Don't collect people's identifiers such as name, or phone number, unless they are necessary for your collection purpose. If the personal information you are asking for isn't necessary to achieve something closely linked to your organisation's functions or activities, you shouldn't collect it.

See the Office of the Privacy Commissioner's website below for more detailed guidance about how to know if the collection of personal information is necessary.

Office of the Privacy Commissioner | Collecting personal information

AskUs | Article | How do I know if collection is necessary? | Office of the Privacy Commissioner

Information privacy principle 2 – Source of personal information

Principle 2 states that personal information should generally be collected directly from the person it is about. The best source of information about a person is usually the person themselves. Collecting information from the person concerned means they know it is being collected and have some control over their information.

It won't always be possible or appropriate to collect information directly from the person concerned. In some situations, organisations may collect information from other sources. For instance:

- if the person concerned authorises collection from someone else
- if the information is publicly available
- if collecting information from the person directly is not reasonably practicable or would undermine the purpose of collection.

Sometimes, information may also be collected from other sources for law enforcement or court proceedings.

See the Office of the Privacy Commissioner's website below for more detailed guidance about sourcing the personal information you need.

Office of the Privacy Commissioner | Principle 2 - Source of personal information - collect it from the individual

Information privacy principle 3 – Collection of personal information from individual concerned

Principle 3 means that organisations should be open about why they are collecting personal information and what they will do with it. This principle is about helping people understand the reasons you are collecting their information.

When an organisation collects personal information, it must take reasonable steps to make sure that the person knows:

- why the information is being collected
- who will receive it
- whether the supply of the information is voluntary or mandatory
- what will happen if the information isn't provided.

Sometimes there may be good reasons for not letting a person know about the collection – for example, if doing so would undermine the purpose of the collection to protect law enforcement investigations, or it's just not possible to tell the person.

See the Office of the Privacy Commissioner's website below for more detailed guidance on the collection of personal information from the person and what you need to tell them.

Office of the Privacy Commissioner | Principle 3 - Collection of information from subject - what to tell the individual

Information privacy principle 3A – Collection of personal information from another source

Principle 3A means that if an organisation collects someone's personal information indirectly, that organisation is required to notify them, unless one of the listed exceptions applies. This principle is about helping people understand the reasons you are collecting their information.

See the Office of the Privacy Commissioner's website below for more detailed guidance on the collection of personal information from the person and what you need to tell them.

Office of the Privacy Commissioner | Principle 3A - Collection of information from another source - what to tell the individual

Information privacy principle 4 – Manner of collection of personal information

Principle 4 states that personal information must be collected in a way that is lawful and seen as fair and reasonable in the circumstances.

What is fair depends a lot on the circumstances like the individual concerned (age and capacity) and the natural sensitivity of the information. Note that threatening, coercive, or misleading behaviour when collecting information from an individual would likely be considered unfair.

If you break the law when collecting information, then you have collected information unlawfully.

What is fair also depends on the circumstances, such as the purpose for collection, the degree to which the collection intrudes on privacy, and the time and place it was collected.

See the Office of the Privacy Commissioner's website below for more detailed guidance on how personal information is collected.

Office of the Privacy Commissioner | Principle 4 - Manner of collection

Information privacy principle 8 – Accuracy, etc, of personal information to be checked before use or disclosure

Principle 8 states that an organisation must check before using or disclosing personal information that it is accurate, up to date, complete, relevant and not misleading.

See the Office of the Privacy Commissioner's website below for more detailed guidance about ensuring that personal information is accurate.

Office of the Privacy Commissioner | Principle 8 - Accuracy of personal information

Health Information Privacy Code 2020

The Health Information Privacy Code (HIPC) 2020 is a specialised privacy code issued under the Privacy Act. It applies to all health and disability service providers, including community, residential, supported living, and NGO disability services.

Where the Privacy Act sets the general rules for handling personal information, the HIPC modifies those rules to provide additional, health-specific requirements for how service providers must collect, use, store and share health information.

If a service provider delivers disability support services, they must comply with the HIPC.

The HIPC sets out 13 Health Information Privacy Rules. These rules largely correspond to the Information Privacy Principles in the Privacy Act and govern the full lifecycle of health information.

Health Information Privacy Code 2020

For more detailed guidance on records creation under the HIPC see the Office of the Privacy Commissioner's fact sheet below:

Office of the Privacy Commissioner | HIPC factsheet 2 - Collection of Health Information

The most relevant Health Information Privacy rules for providers to consider when creating records are:

Rule 1: Purpose of collection of health information

Rule 1 is about only collecting health information if it is needed for a specific purpose.

Organisations collecting health information need to ensure that:

- the information is collected for a **lawful** purpose connected with a function or activity of the health agency; and
- the collection of the information is **necessary** for that purpose.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance about complying with Rule 1.

Rule 2: Source of health information

Rule 2 of the HIPC is about where you collect health information from. Unless an exception applies, you must only collect health information directly from the person the information is about.

This rule makes the person the first port of call for information about themselves. It also enables health information holding organisations to be open about why they are collecting the information, so the individual can make an informed decision about whether to provide it.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance about complying with Rule 2.

Rule 3: Collection of health information from individual concerned

Rule 3 is about telling the person concerned why the information is needed, who else will see it, where it will be stored, and that they have rights to access it and seek correction.

This rule lists what providers have to tell people when they are collecting health information. This explanation should help people decide what information, if any, to provide to health agencies.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance about complying with Rule 3.

Rule 3A: Collection of health information other than from individual concerned

Rule 3A means that if an organisation collects someone's personal information indirectly, that organisation is required to notify them, unless one of the listed exceptions applies.

See the Office of the Privacy Commissioner's website below for more detailed guidance about complying with Rule 3A.

Office of the Privacy Commissioner | HIPC Rule 3A: Notification requirements for indirect collection of health information

Rule 4: Manner of collection of health information

Rule 4 is about not being unfair, misleading or unnecessarily intrusive in collecting the health information.

This rule prohibits health agencies from collecting information unlawfully or unethically. It regulates how information is collected, rather than what is collected.

"Unfair" collection of health information covers a wide spectrum, from bullying, being evasive and devious or misrepresenting the purpose of collection.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance about complying with Rule 4.

Rule 8: Accuracy, etc, of health information to be checked before use or disclosure

Rule 8 requires health agencies to take reasonable steps to ensure health information is accurate, up-to-date, complete, relevant, and not misleading before using it.

This rule prevents decisions about an individual's care from being made on faulty, outdated, or irrelevant information.

See the Health Information Privacy Code below for more detailed information about complying with Rule 8.

Health Information Privacy Code 2020

Public Records Act 2005

The Public Records Act (PRA) establishes a regulatory framework for information and records management across the public sector. The purpose of the PRA is to promote the accountability of government through reliable information management and enhance public confidence in the integrity of government information and records.

Public Records Act 2005 | New Zealand Legislation

Archives New Zealand's (Archives NZ) website contains a useful summary of the key aspects of the PRA for organisations to consider when creating and managing records.

Your responsibilities – Archives New Zealand

The PRA sets out obligations for regulated organisations in how information and records are to be created, maintained, transferred and destroyed.

Responsibilities of regulated organisations are to:

- create and maintain full and accurate records of their affairs, in line with normal business practice
- dispose of information and records as authorised by the Chief Archivist or otherwise by law
- transfer information and records of archival value to Archives NZ.

Under the PRA, the Information and records management standard establishes how to create and manage information and records systematically. It sets out the minimum level of compliance that regulated organisations must meet. Compliance with the standard is mandatory.

Some key areas of the standard related to information and records are:

- regulated organisations must create and maintain full and accurate records of their affairs, in line with normal business practice
- records must be maintained in an accessible form until their disposal is authorised by the Chief Archivist. Note: disposal may include transfer to Archives NZ.

For more detailed guidance about how information should be managed under the PRA and the standard follow the link below.

How to manage your information – Archives New Zealand

Health and Disability Services (Safety) Act 2001 - For providers of residential disability support services

Under the Health and Disability Services (Safety) Act 2001, residential disability support providers are required to comply with the Ngā Paerewa Health and Disability Services Standard.

Ngā Paerewa Health and Disability Services Standard | Ministry of Health NZ

The standard describes how organisations should work with people's information.

Mohiohio/ Information

Te Tiriti

Service providers collect, store and use quality ethnicity data in order to achieve Māori health equity.

As service providers

We ensure the collection, storage, and use of personal and health information of people using our services is accurate, sufficient, secure, accessible, and confidential.

The standard also includes the following requirements for managing people's information.

Ngā paearu/criteria

Service providers shall maintain quality records that comply with the relevant legislation, health information standards, and professional guidelines, including in terms of privacy.

Service providers shall maintain an information management system that:

a. ensures the captured data is collected and stored through a centralised system to reduce multiple copies or versions, inconsistencies, and duplication
b. makes the information manageable
c. ensures the information is accessible for those who need it
d. complies with relevant legislation
e. integrates an individual's health and support records.

Service providers responsible for National Health Index registration of people receiving services shall meet the recording requirements specified by the Ministry of Health.

Records creation obligations in provider contracts

The specific contractual obligations for each provider will depend on their individual contract with DSS and the individual specifications required for the service being provided.

Below are some common examples of the obligations relating to records creation which might apply to different service types.

These example clauses are from agreements in place for some DSS providers as at June 2026. As provider contracts are regularly reviewed and updated, you should always refer to your current individual contract with DSS for details about your specific service requirements.

For more information about the different contracts and service specifications DSS uses with its range of providers follow the link below.

Contracts | Disability Support Services

For more detail about which contractual recordkeeping obligations apply to your service and which specific records you need to create, see your individual outcome agreement and service specifications.

DSS' General Outcome Agreements - some key records creation clauses for providers covered by this agreement

DSS-Outcome-Agreement.pdf

- 13 Further definitions – Records
- Appendix 7– Privacy of personal information
- Appendix 1 - Services, Outcomes to be Achieved, and performance measures
- Appendix 9 – Additional terms to the Framework Terms and Conditions
- 9.2.1 Records

DSS' Tier 1 Service Specifications - some key records creation clauses for providers covered by these specifications

Disability Support Services Tier One Service Specification

- 8.5 Complaints Procedure
- 10. Information Management Requirements
- 10.1 Information Action Plans
- 10.2 Record keeping

DSS' Residential Panel Agreements – some key records creation clauses for providers covered by this agreement

DSS-Residential-Services-Panel-Agreement-Terms-and-Conditions-+-Schedule-1.pdf

- Definitions – Records
- 25. Records
- 25.2 Care Records

DSS' Service Specifications for Needs Assessment and Service Coordination - some key records creation clauses for providers covered by these specifications

Needs-Assessment-and-Service-Co-ordination1.pdf

- 5.10 Information Management
- 5.11.3 Provider Information

DSS' Tier 2 Service Specifications for Community Residential Support Services - some key records creation clauses for providers covered by these specifications

Community-Residential-Support-Services1.pdf

- 6.1 Personal Planning

5.1.2 Practice improvement opportunities for creating care records

The following principles from the Care Records Framework can help guide providers to improve records creation practices.

- Create records with the disabled person where appropriate, reflecting their voice and needs.
- Create accurate records which include different voices and perspectives where appropriate, and reflect the disabled person's whole support journey.
- Create records for the disabled person with an awareness of their enduring value to the person and their whānau, hapū, iwi and community.

Create records with the disabled person where appropriate, reflecting their voice and needs

Why does this principle matter?

- When people receive care records that have been created by and written from the perspectives of others (usually the organisation), it can be disempowering and frustrating, particularly when they have been written in ways that are inaccurate, offensive, or misleading.
- Enabling people to participate in the creation of their own care records where possible – writing with them, rather than only about them – can ensure that their voice, perspective, and needs are accurately recorded. This practice can also ensure that the person understands what is being written about them and why, and can help the records better support the person's memory and understanding of their identity.
- Greater involvement in the creation of care records can mean that less of the information in the records will be a surprise when people later access them. Additionally, if people are involved in the creation of their records, they may be less likely to need to rely on a formal information request to understand their story.

What could good practice look like for providers implementing this principle?

- Make the disabled person aware that records are being created about them, and give them the opportunity to ask questions about, or contribute to, these records.
- Sit alongside the disabled person when creating records about a key decision, explain what is being recorded in a way that makes sense for them, ask for their views, and record their views in their own words.

- Explore different communication methods and options that enable the disabled person to contribute to their records on their own terms, in ways that are meaningful and appropriate for them.
- Identify which information is known to the person when creating the record to help to reduce the need for complex redactions in future access requests. For example, use statements such as “this section was written with or by [person’s name] and they are aware of its contents” or “this information was not disclosed to [person’s name] at this time because…”.

Create accurate records which include different voices and perspectives where appropriate, and reflect the disabled person’s whole support journey

Why does this principle matter?

- Survivors have spoken of the negative impacts of reading care records which contain only the perspective of the system or those working within it. Creating records which contain the voices and perspectives of the person and their support people can help to capture a balanced and accurate picture of the person’s time working with disability support service providers.
- Survivors also described the emotional impacts of reading records which focus only on the negative experiences from their time in care rather than their holistic journey. Historically, recording information only required for organisational needs can mean that a person’s care records are largely made up of care concerns, incident reports, and other events which are traumatic and emotionally challenging to read.
- Individual providers improving the accuracy and consistency of the records they are creating can also help the wider Disability Support system by ensuring that when a person moves services:
    - information can transfer easily
    - receiving providers can interpret records quickly
    - the disabled person does not need to repeatedly retell their story.

What could good practice look like for providers implementing this principle?

- Create records at, or as close as possible to, the time the decisions, events or incidents occur.

- Create full and accurate records about all incidents, responses and decisions affecting the safety and wellbeing, including abuse and neglect, of the disabled people you are supporting.
- Create records which capture the opinions and perspectives of family members or other people supporting the disabled person where appropriate and possible.
- Where you have the disabled person's permission and it is appropriate, help the their support network to understand why key decisions are being made and record how the disabled person and the important people in their lives feel about these decisions.
- Create records which include the positive aspects of a person's support journey. This could include positive comments from those involved in providing support, or any other information which could help to provide the person with a balanced, accurate picture of their working with disability support service providers.
- Ensure that detailed records are created around the transition points of a disabled person's support journey including the reasons for the transition, their views on the change and the support provided during these periods. This can help to capture and preserve the full context of the person's support journey.
- Ensure that detailed records are created around processes involving or requiring the informed consent of the disabled person.
- Ensure that detailed records are created around a disabled person's decision to decline or change the support services they are being provided.
- Develop processes to regularly update documents when the disabled person's circumstances materially change. For example, when someone's goals, support requirements or communication preferences change. It can also be helpful to make a note of why this information is being updated.
- Consider which training to put in place to support your frontline staff to create full accurate and accessible care records.

Create records for the disabled person with an awareness of their enduring value to the person and their whānau, hapū, iwi and community

Why does this principle matter?

- Māori and Pacifica survivors have spoken of the negative impacts of reading and receiving care records which inaccurately captured their cultural identities. These survivors described how receiving such

inaccurate records can be particularly harmful for those people relying on them to understand and reconnect with their own whakapapa and identity.

- Where historical records were created with inaccurate or incomplete information about people's ethnicity and whakapapa, or without the views of the community around the person, survivors described being negatively impacted throughout their adult lives. These impacts included cultural disconnection and the loss of opportunities to reconnect with their own whānau, hapu, iwi and community.
- Creating records that accurately capture ethnicity, iwi and other community identifiers can minimise the chance of people being disconnected from their whānau, whakapapa, community and culture. This practice can also enable a better understanding of the demographics of those receiving disability support, information which can support communities to better understand their people's needs and advocate for resources to support them.

What could good practice look like for providers implementing this principle?

- Create records with an awareness of the key role they can play in helping the disabled person to connect with their identity and whakapapa. Speaking with the disabled person about their relationships with their whānau and wider community can help to accurately capture their cultural identity.
- Create care records which capture the perspectives of the community around the person when key decisions are made about their support.
- Record and capture ethnicity, iwi and other community identifiers in a way that allows for anonymous reporting or responding to requests from community groups to better understand the demographics of those receiving support.
- Record and capture ethnicity, iwi and other community identifiers consistently to allow for anonymous reporting and enable a better understanding of the demographics of those receiving disability support services.
- Look for opportunities to ensure that your organisation's templates and systems allow for and encourage the accurate recording of the cultural identity of the people who are engaging with your service.

Exemplar Care Records

Appendix 2 contains several detailed exemplar documents to help disability support service providers understand what good records creation could look like in practice.

5.2 Managing care records

This section focusses on the practices around managing care records.

This practice area is important to get right as people's records need to be kept safe and secure to make access to them easy and meaningful.

5.2.1 Legal obligations when managing care records

Several pieces of legislation set legal requirements for how providers manage care records.

The excerpts and links below provide an overview of some key legislation for providers to be aware of when managing records.

Privacy Act 2020

The Privacy Act is the foundation of personal information sharing in New Zealand. Every provider, no matter their size or service type, must comply with the Privacy Act. It applies to all personal information an organisation collect, uses, stores, or shares.

The Act sets out the Information Privacy Principles (IPPs), which govern the entire lifecycle of personal information.

https://www.legislation.govt.nz/act/public/2020/31/en/latest/#LMS23352

The most relevant Privacy Principles for providers to consider when manging records are:

Information privacy principle 5 – Storage and security of information

Principle 5 states that organisations must ensure there are safeguards in place that are reasonable in the circumstances to prevent loss, misuse or disclosure of personal information.

See the Office of the Privacy Commissioner's guidance below for more detail on what appropriate security measures could look like in different contexts

AskUs | Article | What security measures are appropriate? | Office of the Privacy Commissioner

Office of the Privacy Commissioner | Security and Internal Access Controls

Information privacy principle 9 – Limits on retention of personal information

Principle 9 states that an organisation should not keep personal information for longer than it is required for the purpose it may lawfully be used.

Note that there may be another law or regulation that requires an organisation to keep information for a certain period of time, for example the Public Records Act 2005.

See the Office of the Privacy Commissioner's website below for more detail on how long organisations should retain personal information.

AskUs | Article | How long does my organisation or business have to keep records for? | Office of the Privacy Commissioner

Information privacy principle 10 – Use of personal information

Principle 10 means that organisations can generally only use personal information for the purpose it was collected, and there are limits on using personal information for different purposes.

Sometimes other uses are allowed, such as use that is directly related to the original purpose, or if the person in question gives their permission for their information to be used in a different way.

See the Office of the Privacy Commissioner's website below for more detail on how long organisations should retain personal information.

AskUs | Article | How long does my organisation or business have to keep records for? | Office of the Privacy Commissioner

Information privacy principle 11 – Limits on disclosure of personal information

Principle 11 means that an organisation may generally only disclose personal information for the purpose for which it was originally collected or obtained. Sometimes other reasons for disclosure are allowed, such as disclosure for a directly related purpose, or if the person in question gives their permission for the disclosure.

For instance, an organisation may disclose personal information when:

- disclosure is one of the purposes for which the organisation got the information
- the person concerned authorises the disclosure
- the information is to be used in a way that does not identify the person concerned

- disclosure is necessary to avoid endangering someone's health or safety
- disclosure is necessary to uphold or enforce the law.

See the Office of the Privacy Commissioner's website below for more detailed information about the disclosure of personal information.

Office of the Privacy Commissioner | Principle 11 - Disclosure of personal information

Health Information Privacy Code 2020

The Health Information Privacy Code (HIPC) 2020 is a specialised privacy code issued under the Privacy Act. It applies to all health and disability service providers, including community, residential, supported living, and NGO disability services.

Where the Privacy Act sets the general rules for handling personal information, the HIPC modifies those rules to provide additional, health-specific requirements for how service providers must collect, use, store and share health information.

If a service provider delivers disability support services, they must comply with the HIPC.

The HIPC sets out 13 Health Information Privacy Rules. These rules largely correspond to the Information Privacy Principles in the Privacy Act and govern the full lifecycle of health information.

Health Information Privacy Code 2020

For more detailed guidance on records management under the HIPC see the Office of the Privacy Commissioner's fact sheet below:

Office of the Privacy Commissioner | HIPC factsheet 5 - Storage, Security, Retention and Disposal of Health Information

The most relevant Health information Privacy rules for providers to consider when manging records are:

Rule 5: Storage and security of health information

Rule 5 of the Code requires health agencies to take 'reasonable security safeguards' to protect health information. This means keeping the information safe from loss, as well as from unauthorised access, use, modification or disclosure.

To comply with rule 5, agencies need to consider what risks there are for the health information they hold, make a plan to address those risks and do what is necessary to carry it out.

Some areas that need to be considered when coming up with a security plan are:

- electronic security – use of email, laptops and portable storage devices, passwords
- operational security – confidentiality agreements with staff and contractors, document tracking and footprinting, staff training
- physical security – entry controls, positioning of whiteboards and computer terminals, locked filing cabinets and storage rooms.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance around complying with Rule 5.

Rule 9: Retention of health information

Health Act regulations require all health information held by providers to be retained for 10 years from the last encounter with the patient, unless transferred to another doctor or to the patient.

The Public Records Act also requires retention by public sector agencies. A Functional Disposal Authority lists how long each type of clinical record must be kept for and what must be done afterwards.

Once the retention periods have passed, Rule 9 of the Code says that health information should be disposed of, securely, unless the health agency has a lawful purpose to retain it.

See the above factsheet on the Office of the Privacy Commissioner's website for more detailed guidance around complying with Rule 9.

Rule 10: Limits on use of health information

Rule 10 is about what you can use health information for. You can only use health information for the purpose it was collected for, unless an exception applies. For example, if the new purpose is directly related to the original purpose, if the new use is authorised by the individual concerned, or if the new use is necessary to prevent a serious threat to health or safety.

See the Health Information Privacy Code below for more information about Rule 10.

Health Information Privacy Code 2020

Rule 11: Limits on disclosure of health information

Rule 11 of the Code prohibits disclosure except where one or more of its exceptions apply.

The rule is quite detailed but the factsheet on the Office of the Privacy Commissioner's website linked below provides an overview on the rules around the disclosure of health information.

Office of the Privacy Commissioner | HIPC factsheet 3 - Disclosure of Health Information

Public Records Act 2005

The Public Records Act (PRA) establishes a regulatory framework for information and records management across the public sector. The purpose of the PRA is to promote the accountability of government through reliable information management and enhance public confidence in the integrity of government information and records.

Public Records Act 2005 | New Zealand Legislation

Archives New Zealand's (Archives NZ) website contains a useful summary of the key aspects of the PRA for organisations to consider when managing records.

Your responsibilities – Archives New Zealand

The PRA sets out obligations for regulated organisations in how information and records are to be created, maintained, transferred or destroyed.

Responsibilities of regulated organisations are to:

- create and maintain full and accurate records of their affairs, in line with normal business practice
- dispose of information and records, as authorised by the Chief Archivist or otherwise by law
- transfer information and records of archival value to Archives NZ.

Under the PRA, the Information and records management standard establishes how to manage information and records systematically. It sets out the minimum level of compliance that regulated organisations must meet. Compliance with the standard is mandatory.

Some key areas of the standard related to information and records management are:

- regulated organisations must create and maintain full and accurate records of their affairs, in line with normal business practice
- records must be maintained in an accessible form until their disposal is authorised by the Chief Archivist
- no one can dispose of, or authorise the disposal of, public or protected records unless they have the authority of the Chief Archivist, or where disposal is required by or under another Act.

For more detailed guidance about how information should be managed follow the link below.

How to manage your information – Archives New Zealand

Disposal of records

Disposal is the process for deciding if, when and how you can transfer, destroy or do something else with your organisation's information and records. Disposal of public sector records is done under the authorisation of the Chief Archivist. This is because these records are the property of government and provide evidence of activity so must be disposed of only if authorised.

Under the PRA, there are five ways you can dispose of information and records - through:

- destruction
- transfer (to Archives NZ or another public office)
- alteration
- sale
- discharge.

Disposal Authorities

Disposal authorities are legal instruments issued by the Chief Archivist that say:

- how long public offices should retain specific types of information and records
- what should happen to the information and records when no longer needed.

For more information about disposal process follow the link below.

Learn more about disposal

As well as there being some general disposal authorities that all organisations can use, each government organisation also needs its own disposal authority specific to its own mandate.

Archives NZ is currently working on a review of the disposal authorities of public offices. They are looking at the existing rules around retaining and disposing of care records. Where necessary, they will also create new rules around their retention and disposal.

Temporary Care Records Protection Instruction

While this work on disposal authorities is carried out, the Temporary Care Records Protection Instruction has been put in place to protect care records from disposal, reinforcing the government's expectations of transparency, accountability, and cooperation from public offices.

This protection instruction withdraws and replaces the disposal moratorium on records relevant to the Abuse in Care Royal Commission of Inquiry originally issued 28 March 2019.

See the link below for more information about the instruction and what it means for your organisation.

Temporary care records protection instruction

To see which records your organisation holds that are covered by the temporary care records protection instruction, follow the link to Archives NZ's care records definition below.

The care records definition

Given the nature of the review of the disposal authorities and the feedback from the people the records are about, it is likely that this work will result in a strengthening of the protections and disposal rules for care records.

DSS will let providers know when Archives NZ plans to remove the Temporary Care Records Protection Instruction and what this means for the sector.

Health and Disability Services (Safety) Act 2001 - For providers of residential disability support services

Under the Health and Disability Services (Safety) Act 2001, residential disability support providers are required to comply with the Ngā Paerewa Health and Disability Services Standard.

Ngā Paerewa Health and Disability Services Standard | Ministry of Health NZ

The standard describes how organisations should work with people's information.

Mohiohio/ Information

Te Tiriti

Service providers collect, store and use quality ethnicity data in order to achieve Māori health equity.

As service providers

We ensure the collection, storage, and use of personal and health information of people using our services is accurate, sufficient, secure, accessible, and confidential.

The standard also includes the following requirements for managing people's information.

Ngā paearu/criteria

Service providers shall maintain quality records that comply with the relevant legislation, health information standards, and professional guidelines, including in terms of privacy.

Service providers shall maintain an information management system that:

a. ensures the captured data is collected and stored through a centralised system to reduce multiple copies or versions, inconsistencies, and duplication

b. makes the information manageable

c. ensures the information is accessible for those who need it

d. complies with relevant legislation

e. integrates an individual's health and support records.

Service providers responsible for National Health Index registration of people receiving services shall meet the recording requirements specified by the Ministry of Health.

Records management obligations in provider contracts

The specific contractual obligations for each provider will depend on their individual contract with DSS and the individual specifications required for the service being provided.

Below are some common examples of the obligations relating to records management which might apply to different service types.

These example clauses are from agreements in place for some DSS providers as at June 2026. As provider contracts are regularly reviewed and updated, you should always refer to your current individual contract with DSS for details about your specific service requirements.

For more information about the different contracts and service specifications DSS uses with its range of providers follow the link below.

Contracts | Disability Support Services

For more detail about which contractual recordkeeping obligations apply to your service and which specific records you need to securely maintain, see your individual outcome agreement and service specifications.

DSS' General Outcome Agreements - some key records management clauses for providers covered by this agreement

DSS-Outcome-Agreement.pdf

- 13 Further definitions – Records
- Appendix 7– Privacy of personal information
- Appendix 1 - Services, Outcomes to be Achieved, and performance measures
- Appendix 9 – Additional terms to the Framework Terms and Conditions
- 9.2.1 Records

DSS' Tier 1 Service Specifications - some key records management clauses for providers covered by these specifications

Disability Support Services Tier One Service Specification

- 8.5 Complaints Procedure
- 10.2 Record keeping
- 10.3 Continuity
- 10.4 Retention of Health Information

DSS' Residential Panel Agreements – some key records management clauses for providers covered by this agreement

DSS-Residential-Services-Panel-Agreement-Terms-and-Conditions-+-Schedule-1.pdf

- Definitions
- 25 Records
- 25.2 Care Records

DSS' Service Specifications for Needs Assessment and Service Coordination - some key records management clauses for providers covered by these specifications

Needs-Assessment-and-Service-Co-ordination1.pdf

- 5.10 Information Management
- 5.11.3 Provider Information

5.2.2 Practice improvement opportunities for managing care records

The following principles from the Care Records Framework can help guide providers towards improved records management practices.

- Store and look after care records in a way which keeps them safe, is respectful, and allows access to be as quick and easy as possible.
- Look for opportunities to identify the care records most valuable to people's identities in description and digitisation processes, including those of value to their whānau, hapū, iwi, and community.

- Consider the enduring value of care records to people and their whānau, hapū, iwi and community in any decisions about their use, retention, transferral, or disposal and look for opportunities to involve them in these decisions.

Store and look after care records in a way which keeps them safe, is respectful, and allows access to be as quick and easy as possible

Why does this principle matter?

- Survivors have spoken of the power that care records can have in helping people to trace and understand their own identities as well as in seeking redress and holding organisations to account. Survivors have described the corresponding emotional distress in becoming aware that there are gaps in their care records. Where these gaps are caused by the organisation losing or destroying their records, Survivors have shared how this can reinforce the feeling of being powerless over their own information and their own lives.
- Staff understanding the value of care records to care experienced people and being conscious of this value when handling, storing and managing care records can help to ensure that the records are respected, protected and able to be made available to the care experienced person when they choose to access them.
- Organisations being conscious of the value of care records to the individual when setting up systems for storage and management can help to embed good practice and enable future access to be quicker, easier and more complete.
- Storing and managing care records in a way that makes them easily accessible and identifiable can also help to ensure that there is better data available to respond to future requests from whānau, hapu, iwi or other community groups who are seeking to understand the interactions between different demographics and care systems.
- Individual providers improving the security, accessibility and consistency of their records management processes can also help the wider Disability Support system by ensuring that when a person moves services:
    - information can transfer easily
    - receiving providers can interpret records quickly
    - the disabled person does not need to repeatedly retell their story.

What could good practice look like for providers implementing this principle?

- Store physical care records with appropriate protections by ensuring that storage is fire safe, mould free, not in a location with a flood risk, and not leaving records lying around or in spaces where they are likely to be handled or read by those where it is not required by their work.
- Store and manage records in line with Archives NZ's Information and Records Management Standard - Information and records management standard – Archives New Zealand
- Store physical copies of care records in line with Archives NZ's guidance on the care and storage of physical records - Storage of physical records – Archives New Zealand
- Store digital copies of care records in alignment with Archives NZ's best practice guidance on digital storage and preservation - Best practice guidance on digital storage and preservation – Archives New Zealand
- Ensure that historical records are accessible throughout their retention period and keep a clear record of where to locate records to enable timely and thorough searches to locate information when people make requests.
- Develop processes or systematised reminders to regularly update documents when the disabled person's circumstances have changed. For example, when someone's goals, support requirements or communication preferences change. It can also be helpful to make a note of why this information is being updated.
- Before transferring or disclosing a disabled person's personal information to another provider, consider the following:
    - Was the disclosure of this information one of the purposes for which the information was originally obtained? For example, was the information collected to refer the person to a support service, or for ensuring continuity of care?
    - Am I disclosing only the minimum amount of information necessary to ensure continuity of care?
    - Has the disabled person or their representative given their permission for this information to be disclosed? Although this is not necessary where the information is being shared for one of the purposes that it was originally obtained, disclosure is always allowed when the person concerned has given their permission.
    - Do any other exceptions to Rule 11 of the Health Information Privacy Code apply which enable or require me to disclose the disabled person's information?

- Whether any of the information requested is out of scope?

See Office of the Privacy Commissioner's factsheet for more guidance on the rules around the disclosure of health information

Office of the Privacy Commissioner | HIPC factsheet 3 - Disclosure of Health Information

- Be transparent if you've lost or destroyed someone's records. Try to locate the missing records and if this is not possible, make people aware of what has happened to their records as early as possible when handling their request for information. Consider reaching out proactively where appropriate to build trust and avoid setting expectations that your organisation won't be able to meet.
- Consider what support could be provided when telling someone that their records have been lost or destroyed to reduce their potential distress.
- Explore ways of creating records that are accessible through secure electronic platforms to save the time and resourcing involved in responding to a future access request.

Look for opportunities to identify the care records most valuable to people's identities in description and digitisation processes, including those of value to their whānau, hapū, iwi, and community

Why does this principle matter?

- Alongside the negative impacts of receiving less information than expected when requesting their care records, survivors have also spoken of receiving thousands of pages of administrative information and duplicates when they were hoping to see their life story and whakapapa.
- Having processes which encourage and facilitate the identification of records generally known to be of the most value to disabled people and other requesters can help ensure that any future provision of access to those records is as meaningful and useful as possible for the requester.
- Storing and managing records in a way that improves the visibility of these key pieces of information can also help your organisation to save time and resources when responding to future access requests from people looking for specific pieces of information.
- Having processes which encourage and facilitate the identification of records generally known to be of the most value to whānau, hapu, iwi and other community groups can help ensure that those groups have

access to the necessary information to understand and advocate for the needs of their members.

What could good practice look like for providers implementing this principle?

- Build an organisational understanding of the types of records likely to be of the most value to disabled people who request their care records. For example, birth certificates, medical documentation, letters from whānau members, support plans or other documents detailing the key decisions or transition points in the disabled person's support journey.
- Consider which records these might be in the context of the specific services provided by your organisation.
- Review your organisation's current description and digitisation or metadata processes to look for possible opportunities to identify and make visible the presence and location of those records generally found to be particularly valuable for requesters.
- Maintain records relevant to the safety and wellbeing of disabled people appropriately, including those concerning abuse and neglect. Record the presence and location of these records in an indexed, logical and secure manner that makes them visible for any future searches and requesters.
- Store and manage records in line with Archives NZ's guidance on the minimum requirements for metadata - Requirements for metadata – Archives New Zealand

Consider the enduring value of care records to people and their whānau, hapū, iwi and community in any decisions about their use, retention, transferral, or disposal and look for opportunities to involve them in these decisions

Why does this principle matter?

- Survivors have spoken of the powerful role that care records can play in helping people to trace and understand their own identities. Survivors and their whānau have also described the adverse impacts of being told that their records are missing or destroyed and explained how this can reinforce feelings of being powerless without autonomy.
- Many existing rules around the use, transfer, retention and disposal of care records have been designed from a perspective of organisational need rather than to best protect the life stories and identities of the people the records are about.

- Providers can build trust in their processes and reduce any perceived power imbalance by looking for opportunities to involve disabled people and their support networks or communities in key decisions about how their records are managed.
- In situations where a records management decision has to be made to comply with legislation or regulation, making people aware of the decisions being made about the management of their records and the reasons for these decisions can still improve transparency and help demystify the processes.
- Providing people with visibility and options wherever possible around the use and management of their care records can lessen the likelihood of people only discovering at the point of trying to access their records that there are gaps in their story or their files have been destroyed.

What could good practice look like for providers implementing this principle?

- Build an organisational understanding of the scope and definition of care records using The care records definition published by Archives NZ and consider which records created and held by your organisation fit within this definition.
- Protect the care records that your organisation is responsible for in alignment with the Temporary care records protection instruction issued by NZ's Chief Archivist to prevent the destruction of care records until Archives NZ completes its review of public office disposal authorities.
- When making decisions about how care records are used, retained, transferred, or disposed of; consider the value of these records to the people they are about and whether there is an opportunity to involve them in the decision. This could be by letting them know the reasoning behind a decision such as a legal or practical need or giving them alternative options such as receiving their own copy of information which your organisation intends to dispose of.
- When a decision is made to dispose of a record, document the full details about why the decision was made and which records are affected by this decision.
- When setting up new processes around the use, transfer, retention and disposal of care records, build in opportunities to reach out to the people who the records are about to provide visibility of the decisions being made. Where possible, provide people with alternative options which might give them more control over the preservation of their story and whakapapa.

5.3 Providing access to care records

This section focuses on the practices around responding to requests and providing access to care records.

This practice area is important to get right as requesting and receiving access to care records can be confusing, demoralising and traumatic. Providing people with clarity and support throughout the process can help to make accessing records a more positive experience.

5.3.1 Legal obligations when providing access to care records

Several pieces of legislation set legal requirements for how providers provide access to care records.

The excerpts and links below provide an overview of some key legislation for providers to be aware of when providing access to records.

Shared redaction guidance

The following guidance was developed by the government to summarise how these legal rules interact in practice and help care record holding organisations to provide meaningful access to care records.

https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Guidance/Shared-redaction-guidance/2024-10-30-Updated-Shared-Redaction-Guidance-for-providing-records-to-people-who-have-been-in-care.docx

Privacy Act 2020

The Privacy Act is the foundation of personal information sharing in New Zealand. Every provider, no matter their size or service type, must comply with the Privacy Act. It applies to all personal information an organisation collect, uses, stores, or shares.

The Act sets out the Information Privacy Principles (IPPs), which govern the entire lifecycle of personal information.

https://www.legislation.govt.nz/act/public/2020/31/en/latest/#LMS23352

The most relevant Privacy Principles for providers to consider when providing access to records are:

Information privacy principle 6 – Access to personal information

Principle 6 states that people have a right to ask for access to their own personal information.

Generally, an organisation must provide access to the personal information it holds about someone if the person in question asks to see it. People can only ask for information about themselves. The Privacy Act does not allow you to request information about another person, unless you are acting on that person's behalf and have written permission.

The detailed rules for how an organisation must respond to a request for personal information are set out in Part 4, Subpart 1 of the Privacy Act 2020.

See the Office of the Privacy Commissioner's website below for more detailed information about how to respond to a request for personal information.

Office of the Privacy Commissioner | Principle 6 - Access to personal information

Information privacy principle 7 – Correction of personal information

Principle 7 states that a person has a right to ask an organisation or business to correct information about them if they think it is wrong.

If an organisation does not agree that the information needs correcting, an individual can ask that an agency attach a statement of correction to its records, and the agency should take reasonable steps to do so.

The rules for how an organisation must respond to a corrections request are set out in Part 4, Subpart 2 of the Privacy Act 2020.

See the Office of the Privacy Commissioner's website below for more detailed information about how to respond to a request for personal information.

Office of the Privacy Commissioner | Principle 7 - Correction of personal information

Health Information Privacy Code 2020

The Health Information Privacy Code (HIPC) 2020 is a specialised privacy code issued under the Privacy Act. It applies to all health and disability service providers, including community, residential, supported living, and NGO disability services.

Where the Privacy Act sets the general rules for handling personal information, the HIPC modifies those rules to provide additional, health-specific requirements for how service providers must collect, use, store and share health information.

If a service provider delivers disability support services, they must comply with the HIPC.

The HIPC sets out 13 Health Information Privacy Rules. These rules largely correspond to the Information Privacy Principles in the Privacy Act and govern the full lifecycle of health information.

Health Information Privacy Code 2020

The most relevant Health information Privacy rules for providers to consider when providing access to records are:

Rule 6: Access to personal health information

People have the right to access information about themselves under rule 6 of the Code. This right has only a few restrictions – for instance, if disclosure would prejudice the requester's physical or mental health or would be an unwarranted disclosure of someone else's affairs. The other grounds for refusal are listed in sections 49-53 of the Privacy Act.

Rule 6 requests must be dealt with promptly. Agencies should either:

- respond (as soon as possible but within 20 working days) saying whether they will provide the information sought, and if not stating reasons for refusal or
- transfer the request (within ten working days) to another agency if the requested information is more clearly connected with the functions and activities of that other agency.

For more detailed guidance on dealing with access requests to health information under the HIPC see the Office of the Privacy Commissioner's fact sheet below:

Office of the Privacy Commissioner | HIPC factsheet 4 - Dealing with access requests

Rule 7: Correction of health information

Under Rule 7, people have the right to ask an organisation to correct information about them if they think it's wrong. If the organisation doesn't agree that the information needs correcting, the individual can ask the organisation to attach a statement of correction to their records and the organisation must take reasonable steps to do so.

Public Records Act 2005

The Public Records Act 2005 (PRA) establishes a regulatory framework for information and records management across the public sector. The purpose of the PRA is to promote the accountability of government through reliable information management and enhance public confidence in the integrity of government information and records.

Public Records Act 2005 | New Zealand Legislation

Archives New Zealand's (Archives NZ) website contains a useful summary of the key aspects of the PRA for providers and other organisations to consider when managing records.

Your responsibilities – Archives New Zealand

The PRA sets out obligations for regulated organisations in how information and records are to be created, maintained, transferred or destroyed. The PRA also covers access to information and records.

Under the PRA, the Information and records management standard establishes how to manage information and records systematically. It sets out the minimum level of compliance that regulated organisations must meet. Compliance with the standard is mandatory.

Some key areas of the standard related to information and records access are:

- regulated organisations must create and maintain full and accurate records of their affairs, in line with normal business practice
- records must be maintained in an accessible form until their disposal is authorised by the Chief Archivist.

For more detailed guidance about how information should be managed follow the link below.

How to manage your information – Archives New Zealand

Health and Disability Services (Safety) Act 2001 - For providers of residential disability support services

Under the Health and Disability Services (Safety) Act 2001, residential disability support providers are required to comply with the Ngā Paerewa Health and Disability Services Standard.

Ngā Paerewa Health and Disability Services Standard | Ministry of Health NZ

The standard describes how organisations should work with people's information.

Mohiohio/ Information

Te Tiriti

Service providers collect, store and use quality ethnicity data in order to achieve Māori health equity.

As service providers

We ensure the collection, storage, and use of personal and health information of people using our services is accurate, sufficient, secure, accessible, and confidential.

The standard also includes the following requirements for managing people's information.

Ngā paearu/criteria

Service providers shall maintain quality records that comply with the relevant legislation, health information standards and professional guidelines, including in terms of privacy.

Service providers shall maintain an information management system that:

a. ensures the captured data is collected and stored through a centralised system to reduce multiple copies or versions, inconsistencies, and duplication

b. makes the information manageable

c. ensures the information is accessible for those who need it

d. complies with relevant legislation

e. integrates an individual's health and support records.

Service providers responsible for National Health Index registration of people receiving services shall meet the recording requirements specified by the Ministry of Health.

Records access obligations in provider contracts

The specific contractual obligations for each provider will depend on their individual contract with DSS and the individual specifications required for the service being provided.

Below are some common examples of the obligations relating to records access which might apply to different service types.

These example clauses are from agreements in place for some DSS providers as at June 2026. As provider contracts are regularly reviewed and updated, you should always refer to your current individual contract with DSS for details about your specific service requirements.

For more information about the different contracts and service specifications DSS uses with its range of providers, follow the link below.

Contracts | Disability Support Services

For more detail about which contractual recordkeeping obligations apply to your service and which specific records you need to provide access to, see your individual outcome agreement and service specifications.

DSS' General Outcome Agreements - some key records access clauses for providers covered by this agreement

DSS-Outcome-Agreement.pdf

- 13 Further definitions – Records
- Appendix 7– Privacy of personal information
- Appendix 1 – Services, Outcomes to be achieved, and performance measures
- Appendix 9 – Additional terms to the Framework Terms and Conditions
- 9.2.1 Records

DSS' Tier 1 Service Specifications - some key records access clauses for providers covered by these specifications

Disability Support Services Tier One Service Specification

- 10.2 Record keeping
- 10.3 Continuity

DSS' Residential Panel Agreements – some key records access clauses for providers covered by this agreement

DSS-Residential-Services-Panel-Agreement-Terms-and-Conditions-+-Schedule-1.pdf

- Definitions - Records
- 25 Records
- 25.2 Care Records
- 30. Reporting and information

DSS' Service Specifications for Needs Assessment and Service Coordination - some key records access clauses for providers covered by these specifications

Needs-Assessment-and-Service-Co-ordination1.pdf

- 5.10 Information Management
- 5.11.1 Individual Information
- 5.11.2 Disability Sector Information
- 5.11.3 Provider Information

5.3.2 Practice improvement opportunities for providing access to care records

The following principles from the Care Records Framework can help guide providers towards improving their records access practices.

- Make each redaction decision on its own circumstances with consideration of the value of the information to the requestor.
- Make people aware of their rights to review or appeal a decision to redact and explain how to do this.
- Empower people to make informed choices about how they engage through the access process and receive their care records.
- Provide tailored support to help all people understand and engage with the access process, including providing accessible information about the process.
- Provide people with the necessary context about care records to help them prepare to receive their information.
- Be transparent about how long it could take to provide people's care records and help them understand why.
- Give whānau and support people the advice they need to support those accessing care records and to access any care records that they are legally entitled to.

Make each redaction decision on its own circumstances with consideration of the value of the information to the requester

Why does this principle matter?

- People often rely on their care records to understand their own identity and story and to support any complaint or redress claim they may choose to make. Survivors and other requesters have described the emotional impacts of receiving their care records and seeing large parts of their information redacted.
- It is important to consider the value of the piece of information to the requester in each decision to redact. Making each decision on its own circumstances can help staff to ensure that they are only redacting information where it is legally necessary (where withholding grounds apply). This will mean that people are provided with as much of their information, and therefore as much of their life story, as possible.

- This principle can help prompt providers to consider the relevance of each piece of information to the requester when weighing up whether that information needs to be redacted due to being sensitive to a third party or which could otherwise be an unwarranted disclosure of another person's affairs.

What could good practice look like for providers implementing this principle?

- Weigh up each decision to redact based on the individual circumstances of the requester's information rather than applying a blanket approach to particular types of information such as carers' information, cell phone numbers, or certain addresses.
- Consider the value of the information as a potential piece of the disabled person's identity and life story when deciding whether it is necessary to redact the information to protect a third party's privacy.
- Where a redaction is necessary and it is possible and appropriate, consider writing a summary of the information being withheld to help the requester understand their context.
- When a redaction is necessary, explain the legal rule and why the redaction decision was made in a way that the disabled person can understand.

Make people aware of their rights to review or appeal a decision to redact and explain how to do this

Why does this principle matter?

- Survivors and other requesters have spoken of the emotional impacts of receiving their care records and seeing large parts of their files redacted, sometimes without adequate explanation of why information was withheld. Many people are not aware of their rights to challenge a decision to redact or are unsure of how to do this, meaning that the record holding organisation's decision to redact can feel final.
- People need to know about the rights they have to challenge a decision to redact to be able to exercise those rights. People need to understand where to go and what to expect from the process. This helps them make an informed decision about whether they will seek a review of a decision to redact.
- Ensuring people understand their rights and the processes they have available to appeal a decision to redact is one way that records holders can uphold and promote people's rights and autonomy through the access process.

What could good practice look like for providers implementing this principle?

- Inform requesters of their rights to appeal a decision to redact when providing their records and communicate this information in a way that makes sense for the individual.
- Have clear processes within your organisation on how to meaningfully respond to concerns or complaints raised by requesters after receiving their information. This could include asking:
    - Are we able to offer to have someone else review the decisions to redact? (Noting this may be difficult in smaller organisations where there are fewer available staff).
    - What are the requester's concerns with the redaction decisions made? What have they shared about why they believe these were unjustified? What information are they hoping to see?
    - Has new information come to light that could change your decision to redact – e.g. the requester has shared information you were not aware of.
    - Where an internal review finds information was withheld unnecessarily, what are possible reasons for this and how could this be avoided in the future – e.g. further support or guidance provided to staff?
    - If your decision to redact is the same after a review, how can you clearly and compassionately communicate with the requester about this? How else can you address the person's concerns? Have you made sure they know what their next options are – including the option to complain to the Office of the Privacy Commissioner or Ombudsman.
    - If the information the requester is seeking from a review of redaction decisions doesn't exist (e.g. it appears it was never recorded or it has since been lost or destroyed), are you able to communicate this to the requester?

Empower people to make informed choices about how they engage through the access process and receive their care records

Why does this principle matter?

- Survivors and other requesters have described their frustrations with the power imbalance they encounter when engaging with care records access processes. People have described a sense that care

records holders are in control of what gets recorded, what gets kept, which pieces of their story people are allowed to access and when they can get access to the information.

- Records holders should provide requesters with options and enable them to make informed choices wherever possible throughout the access process. By doing this, records holders can improve transparency, reduce this power imbalance, and build trust with those engaging with their processes.
- Providing people with choices and options is particularly important in the context of care records. Some requesters may associate the records holding organisations and accessing their records with traumatic experiences from a time when they felt like they had no control.
- Providing options for how people can receive their information is important. Some requesters may have specific accessibility needs or not have a safe and secure place to store or access the records you are providing.

What could good practice look like for providers implementing this principle?

- Provide different options for how requesters can contact your organisation and how they make their request. For example, a form can be a useful way to set out the information needed to proceed with a request for information, but requiring all requesters to fill it out can be an unnecessary barrier to access.
- Engage with people to understand which information they are hoping to receive and what's important to them. Adapt your response to meet what they've asked for, rather than taking a one-size-fits-all approach.

  For example, ask:

  - do they want 'everything' you have about them?
  - do they want answers to key questions and not to be overwhelmed with additional administrative information?
  - do they want information about particular events?
  - are they looking to find a particular document?
  - do they want some information urgently and then have the rest provided later when it's all ready?
- Give the requester options on how (and how often) they want to communicate with your organisation through the process.

For example, some might want:

- regular updates on the progress of a request
- you to leave them alone until their records are ready to be sent
- to only communicate by email or by text, so they can call the records holder back when they're ready (rather than getting a call out of the blue)
- you to only communicate with their support person/representative.

- Provide options for the requester around how they want to receive their records and engage with them to understand what they would prefer.

  For example, by asking:

  - what format they want to receive their records in – paper copy, digital?
  - how they want to receive the records – emailed, couriered to their house, picked up from a safe location, sent to their support person or counsellor?
  - when they want to receive their records (as much as possible), as some people might not want to receive records about their time in care around significant dates.
- Ask requesters for feedback about your access process to give them an opportunity to have a say. This will help your organisation to learn from the feedback and inform future improvements.

Provide tailored support to help all people understand and engage with the access process, including providing accessible information about the process

Why does this principle matter?

- Survivors and other requesters have described their frustrations with the power imbalance they encounter when engaging with care records access processes. This can be particularly challenging and distressing for requesters who have literacy challenges, are neurodiverse or otherwise require support to understand and engage with their care records and the access process.
- Working with the requester to understand their specific needs and what they are hoping to get from the process can make their access journey more meaningful and reduce the risk of frustration or traumatisation. This could be done through offering key information in alternate formats, working with a requester's support network, or offering to connect them to existing support services. Taking

an empathetic, person-centred approach can make the difference between an empowering experience and one that causes distrust and emotional harm.

- Building an organisational understanding of the range of options or supports available to meet the diverse needs of requesters can help staff working on records access feel equipped to identify and respond to these needs and to build trusting relationships with all requesters engaging with their service.

What could good practice look like for providers implementing this principle?

- Ensure any publicly available information about your organisation's records access processes is written in plain language.
- Make key information about your organisation's access process available in alternate formats (Easy Read, Braille, audio, large print and NZSL video).
- Work to ensure that all staff are:
    - aware of care experienced people's rights to request access to information about themselves
    - able to identify a potential request for information
    - aware of where requests for access to information are handled within your organisation and who is responsible for this.
- Provide a single point of contact for people trying to access their records or ask questions about the process.
- Engage with each requester to understand their individual needs and what support they want through the process.
- Proactively consider which support could be offered to requesters when they are going through the process of accessing their records.
- Work with a requester's designated support people or networks to help ensure their experience of accessing their care records is as meaningful and free from barriers as possible.
- Offer reasonable accommodations to support disabled requesters to engage in the records access process. This could include offering to:
    - transcribe key parts of a care record for a blind requester (where the record is in its original paper form and would not otherwise be able to be viewed with a screen reader)
    - use summaries or other methods of tailoring communication where information from care records is unable to be meaningfully shared with the requester.

Provide people with the necessary context about care records to help them prepare to receive their information

Why does this principle matter?

- Survivors and other requesters have spoken about the negative impacts and the emotional toll of receiving their care records. Shared experiences include people receiving:
    - less information than they hoped for
    - files with lots of redactions
    - files containing offensive and outdated language
    - unknown information which they didn't expect.
- By providing as much contextual information about the likely content of care records, organisations can help lessen the emotional impact felt by requesters when receiving and reading their records.
- Understanding what a requester hopes to get out of their request for their records can enable staff to better manage expectations and deliver value to that person regardless of the content of their individual records.
- Being transparent as early as possible with requesters about what care records are and aren't likely to contain can help with building trust.

What could good practice look like for providers implementing this principle?

- Take the time to understand what is important to each individual requester and what they are hoping to get out of the request process.
- Explain to the requester the usual types of documents and information included in care records and do this as early in the request process as is possible and appropriate. For example, the files may contain:
    - lots of administrative documents, duplicates and handwriting
    - documents that weren't created in chronological order or to be easily readable
    - information written from the system's perspective rather than an accurate record of a person's holistic care journey
    - information containing dated and offensive language
    - sensitive information about events you might not be aware of
    - gaps where you might have expected things to be written down and kept on record.
- Explain what redaction means and provide a visual example of what it may look like in the person's records.

- Explain why things might be redacted and the type of information that might be withheld, for example sensitive information about other people.
- Proactively let people know about the possibility of missing or lost information in their request, including records that your organisation may have lost or destroyed.
- Proactively communicate with the requester to notify them of pieces of information which they might find difficult to receive and read. Consider offering to put warnings before these pieces of information so the requester can make the necessary support arrangements when preparing to read them.
- Offer to connect the requester with available supports to lessen the risk of them suffering emotional harm through receiving and engaging with their records.

Be transparent about how long it could take to provide people's care records and help them understand why

Why does this principle matter?

- Survivors and other requesters have shared their frustrations with long delays in receiving their care records. These delays can be particularly frustrating when the person is not informed about why their request is taking longer than they expect.
- Providing people with an understanding of the work involved to prepare their information for release can help to reduce the perceived power imbalance and build trust with the requester.
- People have also expressed their frustrations with not being kept up to date on the progress of their request, particularly when they have been given an expected timeframe and that timeframe has not been met. While there may be very good reasons for such delays, if these are not explained to the requester, this can lead to further distrust of records holding organisations and their processes.

What could good practice look like for providers implementing this principle?

- Explain the release process to the requester in an appropriate level of detail up front, including the factors which may make a request take longer than they might expect. For example:
    - file size
    - needing to order in files from multiple locations
    - the need to review the files to keep other people's information safe.

- Recognise people's rights to access their personal information if they request it (with the exception of applicable withholding grounds).
- Respond as soon as possible after receiving the request (but within the required 20 working days) to confirm whether you will be able to provide the information requested, and if not, to explain the reasons for refusal.
- Provide the requester with an estimated release timeframe which is reasonable in the circumstances of their individual request.
- Explain that before finding and reading through their records, this can only be an estimate and that you will update them if the expected timeframe changes.
- In some situations, it may not be possible to decide whether to grant the access request within 20 working days. The Privacy Act enables organisations to extend the time limit for the initial response to certain requests in some situations, including if a request is for a large quantity of information, and meeting the original time limit would unreasonably interfere with the organisation's operations. In this situation, notify the requester if the release is likely to take longer than the initially estimated timeframe. Extending the time limit for the initial response for a large or complex request must be done within 20 working days after the day the request is received.
- If you are extending the time limits for the response, explain the reasons for the delay at an appropriate level of detail and provide an updated estimated timeframe for the records to be provided. If a request can be responded to and provided within 20 working days, make every effort to do so.
- Offer to provide progress updates to the requester through their preferred method of contact.

Give whānau and support people the advice they need to support those accessing care records and to access any care records that they are legally entitled to

Why does this principle matter?

- Whānau of survivors have described their frustrations with trying to access information about their whānau members and being turned away without an understanding of why.
- Although the law may prevent organisations from giving whānau access to someone else's personal information, communicating this does not need to feel like a dead end for them. It is important to advise the whānau about any information they are entitled to receive, and where appropriate to explain why information is unable to be released

to them. Explaining their options for supporting their whānau member to access the information themselves can provide clarity for the whānau and help to reduce any perceived power imbalance.

- If an organisation understands and can discuss different cultural concepts of privacy, information ownership and the tension between legislation and whānau expectations, they can build trust and demystify the boundaries of records access processes.

What could good practice look like for providers implementing this principle?

- Equip staff working on these requests to understand the areas where whānau may and may not be legally entitled to access information about a care experienced family member.
- Explain at a high level the legal reasons behind these distinctions and the reasons why care records holders might need to withhold some information to comply with the law. For example, to protect the disabled person's privacy.
- Help whānau to receive any information they are entitled to receive.
- Help whānau to understand how they can support their whānau member to request their personal information themselves, should they choose to.
- Build capability of relevant staff members to understand and explain different cultural views of information ownership to better support whānau requesters.

6 Important links and additional information

Information to help people understand their rights and the records access process

If someone you are supporting wants to know more about accessing their care records, the page linked below was created to help provide plain language information to help with people's understanding.

- How to access your care records | Crown response to the Abuse in Care Inquiry

This information is also available in the following alternate formats:

Easy read format

- https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Guidance/Easy-read/2023-06-28-CRU-Accessing-records-easy-read.pdf

Large Print format:

- https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Guidance/Large-print/2023-07-06-CRU-Accessing-records-large-print.docx

New Zealand Sign Language

- https://www.youtube.com/watch?v=FHG6SE71SZA

Audio format

- https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Guidance/Audio/2023-06-28-CRU-Accessing-records-audio.mp3

Braille

- https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Guidance/Braille/2023-06-28-CRU-Accessing-records-braille.zip

Care Records Framework

The government has developed a Care Records Framework (the Framework) to help all care records holders look after records and support care experienced people who want to access them. The Framework also addresses how new care records are created.

The Crown Response Office has drafted detailed guidance material for record holders to help them understand the needs of care experienced people, to describe the values for the ways for records holders to work and to provide principles for records holders with examples of what good practice can look like.

This resource was designed to help organisations to improve their records creation, management and access processes for survivors and other care experienced people.

To request a copy of the draft guidance material or ask a question, please contact Archives NZ via email at rkadvice@dia.govt.nz

Archives NZ regulatory tools and processes

Archives NZ has certain regulatory tools it can use to ensure public sector organisations comply with the Public Records Act 2005.

For more information about Archives NZ's regulatory tools and processes, follow the link below.

Our regulatory tools – Archives New Zealand

DSS auditing tools and processes

DSS also has its own auditing tools and processes which provide an opportunity to review disability service providers and identify areas that may need development.

For more information about DSS' auditing tools and processes, follow the link below.

Audits and evaluation | Disability Support Services

6.1 Other supports available for providers or the disabled people you are working with

Recordkeeping support

If you have recordkeeping questions that your organisation's internal experts aren't able to answer, you can send these questions through to DSS and MSD's Privacy team through the email address below.

privacyofficer@msd.govt.nz

Archives NZ can also help to answer your recordkeeping questions and provide advice through rkadvice@dia.govt.nz

Kōnae

This website, hosted by the Citizen's Advice Bureau, was created to help people access records created by organisations involved in decisions about their guardianship or care.

Nau mai, haere mai

The website also includes a section which provides links to different pieces of guidance for record holding organisations.

Guidelines for record holders

Survivor Experiences Service

The Survivor Experiences Service is for people who were abused in state, faith-based, or other forms of care. The service offers two services for survivors and whānau, an opportunity for people to share their experiences of abuse in care, and support with accessing records about their time in care.

Records Support | Survivor Experiences Service

Appendix 1 - Glossary of terms used in the Provider Guidance

Term	Meaning
Archives New Zealand	Archives New Zealand is the New Zealand government's recordkeeping authority. It is responsible for administering the Public Records Act 2005 and promoting good information management throughout government.
Care experienced person	A care experienced person is someone who was or is in the care, custody, or came to the notice of an organisation that was responsible for their wellbeing. This broad definition includes people working with disability support services.
Care record	Care records contain information about the provision of care services to individuals by State care and non-State care organisations. They include information about both the individual and about the organisation providing care and help care providers to ensure their services are effective and accountable.
Care Records Framework	The Care Records Framework is a tool developed by the New Zealand government in response to the Royal Commission of Inquiry into Abuse in Care. It is designed to help all care record holding organisations improve the way they create, manage, and provide access to care records.
Care records holder	Care records holders are organisations responsible for creating, managing or providing access to care records and include: • State organisations • Faith-based organisations • Non-State organisations

Term	Meaning
Contract	A contract is a legally binding agreement between two or more parties that creates enforceable rights and obligations.
Disability Support Services (DSS)	Disability Support Services (DSS) is a business group in the Ministry of Social Development. DSS coordinates and funds support services to about 55,000 disabled people and their whānau each year. DSS also funds environmental support services for about 100,000 people each year with about 50,000 of these people receiving equipment and modification services.
Disabled person	A disabled person is someone with a long-term physical, cognitive, intellectual, sensory, or mental health impairment that, in interaction with environmental barriers, hinders their full participation in society.
Disposal	Disposal is the process you go through to decide if, when and how you dispose of records as described in the Public Records Act 2005. Public Records Act 2005 | New Zealand Legislation
Health information	Health information in New Zealand refers to personal information about an individual's health, treatment, and disability services. It is protected by the Health Information Privacy Code 2020 and includes medical history, laboratory results, and notes used to provide care.
Legal obligation	A legal obligation is a binding requirement imposed by statute, common law, or contract that necessitates a specific action or omission, enforceable by courts or authorities.
Legislation	Legislation in New Zealand refers to laws created by Parliament or under its authority to set rules, rights, and responsibilities. It is a primary source of law, comprising Acts, regulations, and bylaws.

Term	Meaning
Personal information	Under New Zealand's Privacy Act 2020, personal information is any data that can identify a specific, living person. It is not limited to sensitive or private data; it includes names, addresses, emails, phone numbers, and even photos, recordings, or behavioural patterns that make an individual identifiable.
Provider	A Disability Support Services (DSS) provider in New Zealand is an organisation contracted by the Ministry of Social Development (or Whaikaha) to deliver funded services to disabled people. They include non-governmental organisations, trusts, and private entities that provide essential support, such as community residential services, home help, and equipment, to help people live independently.
Record	A record (information or data) is a piece of evidence or information about the past, especially an account kept in writing but could be in any other form. The definition of what is a record is in the Public Records Act 2005. Public Records Act 2005 | New Zealand Legislation
Redaction	Redaction is the process of hiding or removing sensitive information from documents, audio, or video, often applied to comply with the Privacy Act 2020. It ensures that while personal information is provided upon request, sensitive, third-party, or confidential content is protected. This will often look like blacked-out text.
Requester	A requester under the Privacy Act is an individual seeking access to their own personal information held by a public or private agency. They do not need to be a citizen or in the country, but they cannot request another person's information without authorisation.

Term	Meaning
Royal Commission of inquiry into Abuse in Care	The Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions was established in 2018 to investigate children, young people, and vulnerable adults' experiences of abuse and neglect in State and non-State care in Aotearoa New Zealand between the years of 1950-1999. The Royal Commission ended in June 2024. Its final report Whanaketia, Through pain and trauma, from darkness to light was released in July 2024 and included recommendations to the New Zealand government.
Service specifications	Service specifications are standardised, mandatory, or recommended requirements for services funded by DSS. They define specific outcomes, service components, and quality standards for providers to ensure consistent, person-centred support for people with disabilities.
Survivor	Survivor is used in this context to refer to someone who was abused or suffered harm while in in state, faith-based or another form of care.

Appendix 2 - Exemplar documents to demonstrate good records creation

Good records creation will differ based on the individual circumstances of the provider and the disabled person they support.

These examples are intended to help prompt providers to make the relevant considerations when creating care records. They are not intended to be prescriptive or exhaustive.

Exemplar documents contained in this guidance:

- Privacy Notice
- Individual Consent Form
- Representative 3rd Party Consent Form
- Supported Decision Making Form
- Referral Form

Privacy notice

What a good privacy notice should include

A privacy notice explains how an organisation collects, uses, shares and protects personal information. It helps people understand their rights and how their information will be handled under the Privacy Act 2020, the Health Information Privacy Code (HIPC), and any other relevant legislation.

A good notice builds trust and supports informed decision-making.

Core components of a good privacy notice

A good privacy notice should clearly explain:

- **why information is being collected**

  Examples: to provide disability support services, assess needs, coordinate support with government agencies or other providers, keep people safe

- **what information is being collected**

  Examples: contact details, health information, support needs, assessments, notes, documents

- **how information is being collected**

  Examples: directly from that person, from whānau or representatives, from other agencies, from referrals

- **how information is used**

  Examples: to deliver services, plan support, meet legal obligations, improve service quality

- **when and why information is shared**

  Examples: with other providers involved in support, with agencies such as ACC, MSD/DSS, Whaikaha, when required by law (e.g, Family Violence Act, Health Act, Crimes Act)

- **legal basis for sharing**

  Reference the Privacy Act, HIPC, and any specific Acts that authorise or require disclosure

- **how information is protected**

  Examples: secure systems, access controls, staff training, confidentiality obligations

- **the person's rights**

  Including the right to access, request correction, and ask questions about how their information is handled

- **contact details for privacy queries or complaints.**

Privacy and legal compliance

A privacy notice must:

- comply with the Privacy Act 2020, Health Information Privacy Code and other relevant legislation
- explain when information may be shared without consent, such as
  - serious risk of harm
  - public health requirements
  - family violence safety concerns
  - court orders or compulsory care obligations.
- make it clear that information is only shared when lawful and necessary.

This helps providers avoid over-promising that they “will never share your information” and instead provide individuals (or their representatives) accurate, legally sound explanations for sharing personal information.

Accessibility and cultural safety

For the highest chance of being understood by the widest possible audience, a privacy notice should be easy for people to understand and be culturally respectful. Good practice includes:

- using plain language and short sentences, avoiding complex or legalistic language.
- providing easy read and translated versions.
- reflecting Māori values such as mana, dignity, and collective decision-making.
- using high-contrast formatting, large fonts, accessible layout.
- offering verbal explanations when needed.
- allowing people to bring whānau or support people when discussing privacy.

Checklist for providers

When creating a privacy notice for your organisation, to make it as good as possible, make sure it:

- explains why and how information is collected
- lists what information is collected
- states how information is used
- describes when and why information is shared
- references any relevant legal obligations
- includes rights and contact details
- is accessible, culturally appropriate, and easy to understand
- is reviewed regularly and updated when laws or practices change.

Privacy notice sample structure

Privacy Notice Exemplar Template (for use by disability support service providers)

Providers using this template should adapt it to their individual circumstances and insert their own details.

Introduction

We collect and use personal information so we can provide you with safe, effective services and meet our legal obligations. This privacy notice explains what information we collect, how we use it, when we share it and what your rights are.

What information we collect

We may collect information such as:

- your name and contact details
- information about your health, disability, support needs and goals
- records of the services we provide
- information from assessments, referrals or other agencies involved in your care and support
- information you give us directly, or that your whānau, support people, or representatives give us with your permission.

How we collect information

We collect information:

- directly from you
- from your whānau, support people or legal representatives (with your agreement where possible)
- from other agencies involved in your support (for example, health services, ACC, DSS, etc)
- from referral forms and assessments.

How we use your information

We use your information to:

- provide and coordinate services and supports
- understand your needs and plan with you
- keep you and others safe
- meet our legal and reporting obligations
- improve the quality of our services.

We only use your information for purposes that are lawful and necessary.

When we share your information

We may share your information:

- with other people or agencies involved in your support
- with your whānau or representatives when you agree or when they have legal authority
- when required by law (for example, the Family Violence Act, Health Act, ACC Act, or court orders)
- when there is a serious risk to your safety or the safety of others
- with emergency services if needed to prevent harm.

We only share information when it is lawful, necessary and proportionate.

Legal basis for collecting and sharing information

We follow the obligations set out in the Privacy Act 2020, the Health Information Privacy Code, and the Code of Health and Disability Services Consumers' Rights.

In some situations, other laws may require or allow us to share information, such as:

- Family Violence Act 2018
- Health Act 1956
- Crimes Act 1961
- ACC Act 2001

- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003
- Court orders or compulsory care arrangements.

We will always explain why information is needed and how it will be used.

Your rights

You have the right to:

- ask us for a copy of your information we hold about you
- ask us to correct information you think is wrong
- ask questions about how your information is used
- tell us who you want involved in decisions about your support.

Contact us

If you have questions or concerns about your privacy, or if you want to ask for or correct your information, contact:

[insert role/team]

[insert contact information]

If you are not satisfied with our response, you can contact the Office of the Privacy Commissioner

Office of the Privacy Commissioner | Complain to the Privacy Commissioner

Individual consent form

What a good individual consent form should include

A consent form targeted at the disabled individual themselves supports them giving informed, voluntary consent. It ensures that the person understands what they are agreeing to, can answer yes or no to specific items, and can participate meaningfully in decisions that affect their lives, their wellbeing and their safety.

The form should reflect supported decision-making, respect the person's autonomy and align with New Zealand law.

Core components of a good individual consent form

A good consent form, for the disabled individual, includes:

- **a clear explanation of the purpose of the form**
  (e.g., "This form helps you choose what you agree to and what you don't")
- **the person's name and preferred way of being addressed**
- **a set of clear, specific consent statements**
  Each with options such as Yes / No / I want to talk about this first
- **a supported decision-making section**
  Space to record:
  - Who helped the person understand the form.
  - What support was provided.
  - How the person communicated their decision.
- **a privacy statement**
  Explaining how information will be used, stored, and shared.
- **signature, mark, or alternative form of confirmation**
  (e.g., verbal consent recorded by staff, communication device outputs, etc).
- **witness or staff confirmation section**
  Used only when needed (e.g., alternative communication methods).

Privacy and legal compliance

The individual consent form must:

- comply with the Privacy Act 2020, Health Information Privacy Code, Code of Health and Disability Services Consumers' Rights, Protection of Personal and Property Rights Act 1988 (clarifies legal authority to make decisions) and other relevant legislation
- explain how personal information will be collected, used, and shared
- make it clear that consent can be withdrawn at any time
- note that some information may be shared without consent when required by law, including:
    - serious risk of harm (Privacy Act exceptions)
    - safety concerns under the Family Violence Act 2018
    - obligations under the Crimes Act 1961
    - public health requirements under the Health Act.

Consent should never be presented as the only basis for information sharing.

Accessibility and Cultural safety

A consent form should be easy for users to understand and culturally respectful. Good practice includes:

- using plain language and short sentences avoiding complex or legalistic language
- providing easy read or visual versions
- including prompts for cultural identity, whānau involvement, and preferences
- using high-contrast formatting and large fonts
- allowing time, space, and support for decision-making
- encouraging the person to involve trusted people if they choose
- respecting Māori concepts of mana, whanaungatanga, and collective decision-making.

Informed consent requires a process to properly gain consent, especially in vulnerable communities, it should never be treated as a simple signature-gaining exercise.

Checklist for providers

When creating a good consent form targeted at a disabled adult, providers should make sure their form:

- includes all core components listed above
- aligns with privacy and legal requirements
- is accessible and culturally appropriate
- provides space for supported decision-making
- clearly explains the right to withdraw consent
- uses plain, person-centred language
- avoids unnecessary legal jargon
- can be explained verbally or visually if needed.

Note that if consent is declined, this should also be documented and kept in the person's records, including the reasons why and the person's views on this. This documentation will not necessarily be in the format of an individual consent form.

Individual consent form sample structure

Individual consent form exemplar template (for use by disability support service providers)

Providers using this template should adapt it to their individual circumstances and insert their own details.

[Fictional information has been included in this form to help providers understand what a filled-out form could look like. It is important to note that, in practice, this information would look different for every disabled person].

About this form

This form helps you choose what services you agree to and what you do not agree to.

We will explain everything in a way that works for you. You can ask questions at any time.

You can change your mind or withdraw your consent later.

Your details

Name: [My Name]

Preferred name (if different):

How you prefer to communicate: [By writing]

People you want involved (if any): [My partner's name]

What you are being asked to consent to

Please read (or have someone read to you) each statement.

Choose Yes, No, or I want to talk about this first.

- I understand why you are collecting my information (Y/N/?)
- I agree that you can use my information to provide services and support (Y/N/?)

- I agree you can share my information with other people or agencies involved in my support (Y/N/?)
- I want you to talk to me before sharing my information with new people or agencies (Y/N/?)
- I agree to take part in the services or support described to me (Y/N/?)
- I understand I can stop or change my consent at any time (Y/N/?)

Remove or add statements as needed.

Supported decision-making (if used)

Did someone support you to understand this form (Y/N)

Name of supporter: [My partner's name]

Relationship/role: [Partner and support person]

How they supported you: [They helped me to understand the questions and fill out the form]

Privacy and Information use

We collect and use your information so we can provide services to look after you and keep you safe.

We follow the Privacy Act 2020, the Health Information Privacy Code, and the Code of Health and Disability Services Consumers' Rights.

We may share your information:

- with people or agencies involved in your support
- with your whānau or representatives when you agree or when they have legal authority
- when required by law (for example, safety concerns, court orders, public health requirements)
- when there is a serious risk to your safety or the safety of others.

You can ask to see or correct your information at any time.

Your confirmation

By signing below, you're saying that:

- you understand what you are agreeing to
- you had the chance to ask questions
- you chose your answers freely
- you know you can change your mind later at any time.

Your signature or mark: [Person's signature]

Date: [26/03/2026]

If the person uses an alternative method of communication (e.g., verbal consent, communication device), record details here:

Staff/witness confirmation (if needed)

[Staff member's signature]

[My partner's signature]

Representative (3rd Party) consent form

What a good representative (3rd party) consent form should include

A consent form targeted at the disabled individual's representative confirms that the representative (such as a whānau member, friend, advocate, or support worker) understands their role in supporting a disabled person to make their own decisions.

It reinforces that:

- the disabled person is the decision-maker
- the representative's role is to support understanding and communication, not to give consent on the person's behalf
- a representative may only give consent if they hold legal authority (e.g., Enduring Power of Attorney, welfare guardian under the PPPR Act).

This protects the person's rights and ensures providers do not rely on informal consent from someone that has no legal mandate.

Core components of a good representative consent form

A good consent form, for the disabled individual's representative, includes:

- the representative's name and relationship to the disabled person
- contact information
- affirmations that clarify:
    - the disabled person's right to make their own decisions
    - the representative's role in supporting understanding
    - the limits of the representative's authority
    - the expectation to respect the disabled person's wishes for their care and support.
- a privacy statement explaining how the information will be used and stored
- signature and date fields
- [Optional] cultural identity and communication preference prompts.

Privacy and legal compliance

The form must align with:

- Privacy Act 2020, Health Information Code
- Code of Health and Disability Services Consumers' Rights
- Protection of Personal and Property Rights Act 1988 (clarifies legal authority to make decisions)
- Family Violence Act 2018 (safety-based information sharing)
- Crimes Act 1961 (harm, neglect, exploitation).

The form should clearly state:

- information will be stored securely
- information will only be shared with people involved in the disabled person's care and support
- information may be shared without consent only when required by law or to prevent serious harm
- the representative is not authorised to make decisions unless they hold formal legal authority.

Accessibility and cultural safety

A good representative consent form is easy to understand, culturally respectful and targeted at the representative. Providers should aim to:

- use plain language and short sentences over complex or legalistic language
- offer easy read versions
- include prompts recognising cultural identity, whānau involvement and preferences
- use high-contrast formatting and large fonts
- allow time and support for the representative to understand their role
- recognise Māori values such as mana, whanaungatanga, and collective decision-making.

Checklist for providers

When creating a good consent form targeted at a disabled person's representative, providers should make sure their form:

- clarifies the representative's role and limits
- states the disabled person remains the decision-maker
- aligns with privacy and legal requirements
- is accessible and culturally safe
- uses language that reinforces the autonomy of the disabled person
- records any legal authority (Enduring Power of Attorney, welfare guardian etc) if applicable
- avoids implying the third party can consent unless legally authorised.

Representative (3rd party) consent form sample structure

Representative consent form exemplar template (for use by disability support service providers)

Providers using this template should adapt it to their individual circumstances and insert their own details.

[Fictional information has been included in this form to help providers understand what a filled-out form could look like. It is important to note that, in practice, this information would look different for every disabled person].

For whānau, friends, advocates and other supporting a disabled person.

About this form

This form confirms that you understand your role in supporting the person to make their own decisions.

You are not being asked to give consent on their behalf unless you have formal legal authority (such as Enduring Power of Attorney or a Welfare Guardian order).

Your role is to help the person understand information and communicate their own choices.

Details of the person being supported

Name: [My name]

Preferred name (if different):

How they prefer to communicate: [In writing]

Your details

Name: [My partner's name]

Relationship to the person: [Partner and support person]

Phone: [My partner's cell phone number]

Email: [My partner's email address]

Your role in supporting the person:

Please read each statement and tick to show you agree.

- ☐ I understand that the person has the right to make their own decisions.
- ☐ I will support the person to understand information in a way that works for them.
- ☐ I will help the person communicate their own choices.
- ☐ I will only speak on the person's behalf when they ask me to.
- ☐ I will respect the person's wishes, preferences, and communication style.
- ☐ I understand that I am not giving consent on the person's behalf unless I have legal authority .
- ☐ I will tell staff if the person's preferences or communication needs change.

If you do have legal authority (EPA or Welfare Guardian), please record it here:

- ☐ Yes, I have enduring Power of Attorney for my partner

  [My name]

Privacy and information use

We collect your information so we understand your role in supporting the person.

We follow the Privacy Act 2020, the Health Information Privacy Code, and the Code of Health and Disability Services Consumers' Rights.

We may share your information:

- with staff involved in the person's support
- with the person themselves
- when required by law (e.g. safety concerns, court orders, public health requirements)
- when there is a serious risk to someone's safety
- when working with other organisations involved in the care and support of the person.

Your information will be stored securely.

Your confirmation

By signing below, you are saying that:

- you understand your role in supporting the person
- you know you are not the decision-maker unless you have legal authority
- you agree to support the person's autonomy and preferences
- you understand how your information will be used.

Your signature: [My partner's signature]

Date: [xx/xx/xx]

Staff/witness confirmation (if needed)

Only complete this section if the person or third party requested a witness, or if alternative communication methods were used.

Name:

Role:

Signature:

Date:

Provider contact details

If you have questions about this form or your role:

[Insert role/team]

Phone: [Provider's phone number]

Email: [Provider's email address]

Address: [Provider's physical address]

Supported decision-making form

What a good supported decision-making form should include

A supported decision-making form affirms the disabled person is the decision-maker and that they have the right to make their own choices with support. It documents the person's preferences, communication needs, and trusted supporters so that everyone involved understands how to uphold the person's dignity and autonomy.

This form is not about transferring decision-making to someone else; it is about recording how the person wants to be supported to make their own decisions.

Core components of a good supported decision-making form

A strong supported decision-making consent form includes:

- the person's name and preferred name
- their communication preferences
- names and relationships of trusted supporters
- statements affirming the person's rights, such as:
    - "I can say yes or no"
    - "I can ask for more information"
    - "I can change my mind"
    - "I can choose who helps me understand things"
- a section describing how the person was supported
- signature, mark, or alternative confirmation
- witness or staff confirmation (if needed).

This form works best when used alongside the individual and representative (3rd party) consent forms.

Privacy and legal compliance

A supported decision-making form should include a privacy statement explaining:

- how the person's information will be used
- who it may be shared with
- how it will be stored

- that information may be shared without consent only when required (or permitted) by law
- the key pieces of legislation the provider operates under (e.g., the Privacy Act 2020, HIPC, Code of Health and Disability Services Consumers' Rights, Protection of Personal and Property Rights Act 1988, Family Violence Act 2018, Crimes Act 1961).

The form should also clarify that supported decision-making does not give supporters legal authority to make decisions unless they hold formal powers (EPA or Welfare Guardian).

Accessibility and cultural safety

A good supported decision-making form is accessible and culturally respectful. When building their own form, Providers should:

- use plain language and short sentences
- offer Easy Read or visual formats
- include options for different communication methods
- respect cultural identity, tikanga, and whānau involvement
- allow time, breaks, and support to ensure understanding of the form
- encourage the person to choose who they want involved.

This form should reflect the person's identity and their choices, not just their disability.

Checklist for providers

Providers should make sure their form:

- includes all core components listed above
- affirms the person's rights and autonomy
- aligns with privacy and legal requirements
- is accessible and culturally safe
- records the disabled person's communication preferences
- records the disabled person's trusted supporters
- documents how the disabled person was supported
- avoids legalistic or overly technical language.

Supported decision-making form sample structure

Supported decision-making consent form exemplar template (for use by disability support service providers)

Providers using this template should adapt it to their individual circumstances and insert their own details

[Fictional information has been included in this form to help providers understand what a filled-out form could look like. It is important to note that, in practice, this information would look different for every disabled person].

For documenting how a disabled person wants to be supported to make their own decisions.

About this form

This form records how you want to be supported to understand information and make your own decisions.

You are the decision-maker. You can ask for help, take your time, and choose who supports you.

You can change your mind at any time.

Your details

Name: [My name]

Preferred name (if different):

Date of Birth: [My D.O.B]

How you prefer to communicate:

- ☐ Talking
- ☐ Writing
- ☐ Sign language
- ☐ Communication device
- ☐ Pictures/symbols
- ☐ Gestures
- ☐ Other: _____

Languages you use: [English]

Cultural identity (optional):

People you want to support you

List the people you trust to help you understand information or communicate your decisions.

Name	Relationship	How they support you
[My partner's name]	[Partner and EPA holder]	[My partner helps me to understand information and then helps me to make decisions and communicate my decisions when I need support].

These people support you – they do not make decisions for you unless they have legal authority (e.g., EPA or Welfare Guardian)

If someone does have legal authority, record it here:

- ☐ [My partner has enduring power of attorney for me]

_____

_____

Your rights

Please tick to show what you understand and agree with

- ☐ I can ask for help to understand information
- ☐ I can say yes or no
- ☐ I can ask for more time
- ☐ I can choose who supports me
- ☐ I can change my mind
- ☐ I make my own decisions unless someone has legal authority

How were you supported today?

Record how the person was supported to understand this form

- ☐ Easy Read
- ☐ Pictures, diagrams or other visual prompts
- ☐ Communication device
- ☐ Support person helped explain
- ☐ Breaks were offered
- ☐ Other:

_____

How you communicated your decision:

- ☐ Speech
- ☐ Sign
- ☐ Device
- ☐ In writing
- ☐ Gestures
- ☐ Behaviour
- ☐ Other:

_____

Privacy and information use

We collect this information so we understand how to support you to make decisions.

We follow the Privacy Act 2020, the Health Information Privacy Code, and the Code of Health and Disability Services Consumers' Rights.

We may share your information:

- with staff and other organisations involved in your support
- with the supporters you choose
- when required by law (e.g., safety concerns, court orders, public health requirements)
- when there is a serious risk to someone's safety.

Your information will be stored securely.

You can ask to see or correct your information at any time.

Your confirmation

By signing or marking below, you are saying that:

- you understand this form
- you had the support you needed
- you chose who supports you
- you know you can change your mind.

Your signature (or mark):

[My signature]

_____

Date: [xx/xx/xxx]

If you use another method to confirm (e.g., verbal, device, etc), record details here:

_____

Staff/witness confirmation (if needed)

Only complete this section if the person requested a witness or used an alternative communication method.

Name:

Role:

Signature:

Date:

Provider contact details

If you have questions about this form or your information:

[insert role/team]

Phone: [Provider's phone number]

Email: [Provider's email address]

Address: [Provider's physical address]

Referral form

What a good referral form should include

A referral form connects a disabled person with a service provider who can support their identity, care and wellbeing, safety, and rights. It ensures the person has been involved in the process and that informed consent has been obtained where appropriate. A good referral form will also ensure that the receiving provider has the information they need to offer safe, considered, culturally appropriate, and effective support.

The form must be privacy-compliant, culturally inclusive, and grounded in supported decision-making.

Core components of a good referral form

A good referral form includes information about the following core components:

Consent and decision making

- Clear record of whether the person has agreed to the referral
- How consent was obtained (verbal, written, supported decision-making)
- Whether a legally authorised representative was involved
- The date or timeline of when consent was given
- Explanation of any situations where consent was not possible or not required (e.g., serious safety concerns).

Person's information

- Name and preferred name
- Date of birth
- Address and contact details
- Pronouns and/or gender identity (where relevant)
- Ethnicity, iwi, hapū (if the person chooses to share)
- Cultural identity and practice important to the person (where relevant).

Communication needs

- Preferred communication method (speech, sign, device, writing, pictures)
- Accessibility needs (interpreters, Easy Read, sensory considerations)
- Preferred contact method (phone, text, email, through a support person).

Agencies, organisations, and legal contacts

- Current supports, and the agencies or organisations involved in their care
- Key professionals (GP, mental health services, ACC, DSS, Whaikaha, school, etc)
- Any legal orders or roles (Enduring Power of Attorney, Welfare Guardian, Intellectual Disability Compulsory Care orders).

Support needs (where relevant to the referral)

Covering the whole person, including:

- Physical
- Emotional
- Spiritual
- Cultural
- Social
- Whānau and community connections
- Safety and wellbeing needs.

Supported decision-making

- How the person was supported to understand the referral
- Who helped them
- How they communicated their decision
- Any tools used (Easy Read, pictures, devices).

Risk and safety information (where relevant to the referral)

- Any known risks or concerns
- Types of harm or abuse (if relevant)

- Steps already taken to keep the person safe
- Any urgent or immediate concerns.

Requested support

- What the referrer is asking the receiving provider to do
- Any time-sensitive needs
- Any specific cultural or accessibility requirements
- Contact details of the referrer or person who can be contacted about the referral.

Privacy and legal compliance

The referral form must align with the requirements under:

- The Privacy Act 2020.
- Health Information Privacy Code.
- Code of Health and Disability Services Consumers' Rights.
- Any other legislation relevant to the provider's work (e.g., Family Violence Act 2018, Crimes Act 1961, Protection of Personal and Property Rights Act 1988).
- Ngā Paerewa Health and Disability Services Standard (for providers of residential support).

Checklist for providers

When creating a referral form, providers should make sure their form:

- includes all the core components listed above
- aligns with privacy and legal requirements
- includes a clear privacy statement
- explains how information will be stored, used, and shared
- is accessible and culturally safe
- records consent clearly
- Documents communication needs, preferences and supporters
- includes risk and safety information where relevant
- provides space for next steps and follow-ups.

Referral form sample structure

Referral form exemplar template (for use by disability support service providers)

Providers using this template should adapt it to their individual circumstances and insert their own details.

[Fictional information has been included in this form to help providers understand what a filled-out form could look like. This information would look different for every disabled person].

For referring a disabled person to services or supports.

About this form

This form helps us understand who is being referred, what support they need, what/who/where they are referred to and who is involved.

We use this information to make sure the person receives the right services in a safe and coordinated way.

We will explain how we use and protect information in the privacy section below.

Details of the person being referred

Name: [My name]

Date of birth: [02/04/1984]

Address: [23 Gibson Avenue, Taumaranui]

Phone/ preferred contact method: [email address]

Preferred way to communicate: [Prefers written communication]

Primary languages: [English]

Referral source:

Who is making the referral?

- ☐ The person themselves
- ☐ Whānau/family
- ☐ Support worker
- ☐ Advocate
- ☐ Health or disability provider
- ☐ Other (please describe):

_____

Name of referrer:

Person or Organisation (if any): [my partner's name]

Phone: [023 650 78xx]

Email: [my partner's email address]

Reason for referral

Please describe why the person is being referred and what support is needed.

[My name is being referred to this service to assist him with getting access to the housing modifications he needs to live his good life.]

_____ [My name is generally well supported by his family however he is having trouble getting in and out of the shower without help. I have talked to him about how this service can help with modifications to make showering safer and easier for him and he is very excited to have these modifications made to increase his independence].

_____

_____

[Examples of reasons why a disabled person might be referred to a service: support coordination, assessments, equipment, housing support, wellbeing support, safety concerns, communication support].

Current supports and organisations involved

List any people or agencies currently supporting the person (e.g., GP, mental health services, ACC, DSS, Whaikaha, school, community group).

Organisation/Person	Role	Contact details
[My GP's name]	[GP]	[027 363 66xx]
[My coordinator's name]	[ACC coordination]	[027 657 34xx]

Consent to share information

Has the person agreed to this referral?

- ☐ Yes
- ☐ No
- ☐ Partially
- ☐ The person is not able to consent right now
- ☐ Consent was given by a legally authorised representative

If yes or partially, record details:

How the person gave consent (e.g., verbal, written, communication device):

[My name provided written consent after I explained that I would be providing information to the service about his current difficulties showering and his relevant support needs. I explained to him that this information would be used by the service to help make sure that the shower modifications would meet his physical support needs. I made sure that he understood the process we are going through before beginning with filling out this referral form.]

If a representative gave consent, record their name and authority:

If the person has not consented, explain why the referral is still being made (e.g., serious safety concerns, legal requirements, etc):

Privacy and information use

We collect the information in this form so we can understand the person's needs and provide safe, effective support.

We follow the Privacy Act 2020, the Health Information Privacy Code, and the Code of Health and Disability Services Consumers' Rights.

We may share information:

- with services involved in the referral
- with the person and their chose supporters
- when required by law (e.g., safety concerns, court orders, public health requirements)
- when there is a serious risk to someone's safety

Information will be stored securely.

Safety or urgent concerns (if any)

If there are immediate safety concerns, please describe them here:

[My name has had several falls in the shower recently when trying to shower independently, I have since been helping him and this lessens the risk but having these modifications made as soon as possible will help to lessen the risk and increase my names' autonomy.

They are well supported and connected socially and culturally and otherwise physically healthy however so there are no immediate safety concerns.]

[Examples of safety issues: risk of harm, family violence concerns, urgent health needs].

Additional information

Include other details that will help us understand the person's needs

[My name has a degenerative disorder which means that he will need more support as he gets older. He used to able to shower independently but recently has had several tripping incidents.]

[This is a concern for all of his family and support network as we work hard and are committed to enabling him to live his life with as much autonomy as possible. Needing to shower with my support limits when he can shower and affects his confidence and mental wellbeing as he is very proud of his ability to be independent and knows that his physical support needs are likely to increase as he gets older.]

Referrer confirmation

By signing below, you confirm that:

- The information provided is accurate to the best of your knowledge
- You have explained the referral to the person (where possible)
- You have obtained the consent of the person (where possible)
- You understand how the information will be used

Signature: [My partner's signature]

Date: [30/03/2026]

Referrer's contact details

If you have questions about this referral:

[Insert role/team/contact point]

Phone: [023 650 78xx]

Email: [my partner's email address]

Address: [23 Gibson Avenue, Taumaranui]

7348DSS JULY 2026

Disability Support Services

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA