

INQUIRY INTO THE MINISTRY OF SOCIAL DEVELOPMENT'S COLLECTION OF INDIVIDUAL CLIENT-LEVEL DATA FROM NGOS

04 APRIL 2017

"Rightly, the idea of our personal data being collected or passed on, without our permission, has a tendency to spark alarm in New Zealand. But the good news is that, when it comes to data analytics, we can achieve an astonishing amount without the need for personalised data.

Between the extremes of personalised data and population level data is the useful (and often misunderstood) category of de-identified or "confidentialised" data. It tells the same story about the experiences of an individual, across aspects like health, employment, education and justice. However, crucial pieces of personal data are absent, such as names, addresses, birth dates and other details that would identify individuals. For researchers and policy makers, large sets of this de-identified data are gold. They give us everything we need and nothing we don't."

(Professor Rhema Vaithianathan: *Data - the heavy lifting can be done blind*, Dominion Post, 28 March 2017)

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Executive Summary

- 1. In 2016 the Ministry of Social Development (MSD) began rolling out funding contracts that required non-government organisations (NGOs) to disclose individual client-level data (ICLD) about service users. Previously, personal information about clients was held at the NGO level and MSD did not require it. This policy change is being applied to all MSD-funded NGOs, including those that deal with sensitive issues such as psychological counselling and family violence. NGOs are deeply concerned about the impact this policy will have on their clients and ongoing service viability.
- 2. I have conducted an inquiry under section 13 of the Privacy Act 1993, which sets out my functions including powers to make public statements in relation to matters affecting privacy, to receive and invite representations from members of the public on such matters, and to inquire into any matter or practice that may infringe on individual privacy.
- 3. No NGO receives government funding as of right, and it is not only legitimate, but important that Government takes steps to ensure the efficacy of any programme it funds. It needs good information in order to do so.
- 4. However, insufficient consideration has been given to means by which Government might achieve those legitimate aims in ways that do not involve the collection of excessive or unnecessary personal information.
- 5. The manner in which the policy change has been effected risks undermining the trust between individual service users and NGOs. This may deter some of the most in need from accessing necessary help because of the NGO's inability to keep details private, even from MSD.
- 6. Such an outcome would not only have an adverse affect on the individuals concerned and NGOs, but would not serve the public interest. Unfunded or deterred (potential) service users would not feature in data being used to inform government policy. They would effectively become invisible.
- 7. The ICLD policy has features that are likely to be replicated across a range of programmes in order to achieve the Government's "social investment strategy". It is a significant change in the way social services are delivered, and it is important to get it right. I have made a number of recommendations that I hope will enable Government to learn from this experience, and to ensure future initiatives can proceed without undermining the trust and confidence necessary for the effective engagement of those in our communities most in need of support.
- 8. I have concluded that the ICLD policy, as implemented, is inconsistent with the principles of the Privacy Act and should therefore be amended.

John Edwards Privacy Commissioner

1.0 Recommendations

1.1 Recommendation one:

MSD should consider alternative methods for accomplishing its goals such as having the information collated and analysed by Statistics New Zealand in the Integrated Data Infrastructure

1.1.1 My inquiry reveals that this would provide the highest level of confidence, while still meeting many of the Government's goals. As such, I regard recommendation one as the preferable option. If that is not possible, the following recommendations intend to mitigate the risks I have identified.

"Our preference would be for ICLD to be either made optional (for both provider NGOs and for individual clients), or scrapped altogether. If neither is possible, then we would like prevention programmes such as ours to be excluded from ICLD requirements." (Written submitter)

1.2 Recommendation two:

MSD must ensure its information collection practices do not deter vulnerable individuals from receiving necessary help

- 1.2.1 I recommend that MSD considers how it can meet its policy objectives in ways that infringe less on personal privacy and reduce the risk of unintended adverse consequences for New Zealand's most vulnerable people.
- 1.2.2 Possible means of achieving this include:
 - a level of tolerance for clients to opt-out of providing their information;
 - scope for providing anonymised information; and
 - excluding sensitive services from the policy until MSD has analysed whether and the extent to which ICLD collection and analysis for non-sensitive services has achieved its policy objectives.

"We surveyed 17 of our clients (adult male survivors of sexual abuse) and all said that they would cease all involvement if their personal details were to be shared with any government department." (Survey respondent)

1.3 Recommendation three:

MSD must ensure that its purposes for collecting, holding, using and disclosing information are specific, relevant to its functions and clearly conveyed, and the information collected is necessary to achieve these purposes

"We believe there are alternative ways of fulfilling the MSD's objectives in the new Building Financial Capability policy without the requirement to provide identifiable client data but which we have not yet been given the opportunity to discuss with the MSD." (Survey respondent)

1.4 Recommendation four:

MSD must ensure that its security procedures for holding, using and disclosing ICLD are robust, well-documented and transparent

Many of our clients are actively being stalked, and others have relocated to a confidential address for their safety. We advise these clients not to share their details with anyone. Confidential contact details are an important part of our work and clients may well decline the services they need. (Written Submitter)

2.0 Introduction

- 2.1 This report sets out the findings of my inquiry into the Ministry of Social Development's (MSD) collection of individual client level data (ICLD) from non-government organisations (NGOs) that are contracted by MSD to provide social services.
- 2.2 The purpose of this inquiry was to examine the impacts on individual privacy of the funding contracts that require service providers to pass ICLD to MSD, and whether the contractual provisions are consistent with the principles in the Privacy Act 1993.

Why have we undertaken this inquiry?

- 2.3 All Government departments collect and move personal information as they carry out their functions. We are often asked to help ensure new initiatives involving personal information are designed consistently with the Privacy Act and we have invested considerably in our capacity to offer this support. It is usually preferable to work alongside officials to help identify and resolve privacy risks in advance. In this case, NGOs were effectively presented with a fait accompli, leaving it only possible for me to review the policy after the fact.
- 2.4 A number of people contacted me expressing concern about the potential privacy impacts of this policy. I considered the best approach to address these concerns under my functions as authorised in section 13 of the Privacy Act:
 - 2.4.1 to make public statements in relation to any matter affecting individual privacy;
 - 2.4.2 to receive and invite representations from members of the public on any matter affecting individual privacy;
 - 2.4.3 to consult and cooperate with other persons and bodies concerned with the privacy of the individual;
 - 2.4.4 to make suggestions in relation to any matter that concerns the need for, or the desirability of action in the interests of individual privacy;
 - 2.4.5 to provide advice (with or without a request) to a Minister or an agency on any matter relevant to the operation of the Privacy Act; and
 - 2.4.6 "to inquire generally into any matter if it appears that the privacy of the individual is being, or may be infringed thereby".
- 2.5 Additionally under Part 8 of the Act, I am able to investigate a matter that is or may be an "interference with privacy". That term is defined in section 66 as a breach of one of the information privacy principles, together with some harm or loss, adverse affect on the individual's rights or benefits or significant humiliation, loss of dignity or significant injury to the individual's feelings. It is not a simple matter to determine in advance if a policy amounts to a breach.
- 2.6 Section 14(a) of the Privacy Act requires that I have due regard for the protection of human rights and social interests that compete with privacy, including the general desirability of a free flow of information and the recognition of the right of government to achieve its objectives in an efficient way. In doing so, I acknowledge the legitimacy of the Government's intention to assess the effectiveness of social services and prioritise its investment decisions.

- 2.7 My primary sources of information for this inquiry were:
 - submissions received from NGOs through meetings and written correspondence with my office;
 - an online survey of 548 NGO respondents;
 - documents regarding the ICLD policy provided by MSD; and
 - comments received from MSD on a draft of this report.
- 2.8 The timeline for the inquiry is attached as Appendix A.

3.0 Background

3.1 Social Investment Approach

- 3.1.1 Better use of data underpins the Government's "social investment approach". MSD's collection of ICLD sits within this broader context of Government focus on evidencebased policies backed up by "big data" to inform spending on government services.
- 3.1.2 According to the New Zealand Treasury, "Social Investment is about improving the lives of New Zealanders by applying rigorous and evidence-based investment practices to social services. It means using information and technology to better understand the people who need public services and what works, and then adjusting services accordingly. What is learnt through this process informs the next set of investment decisions."1

3.2 **Community Investment Strategy**

- 3.2.1 The ICLD policy is part of MSD's wider Community Investment Strategy, which was released in June 2015 and updated in August 2016. This Strategy follows on from the Investing in Services for Outcomes work programme, which began in 2012 with the aim of targeting services based on evidence of effectiveness.
- 3.2.2 The Community Investment Strategy aims to implement a social investment approach to MSD's contracting for programmes and services. MSD says that a key objective of the Strategy is "to better align funding to those with the highest need, and to invest in programmes, services and providers that can best meet those needs."²
- 3.2.3 The Strategy has six key elements, two of which provide the basis for the ICLD policy:
 - building the evidence base so funding is directed at services that have proven results; and
 - improving the quality of data collection so services can be targeted where needed most.3

The ICLD Policy 3.3

What is ICLD?

3.3.1 MSD defines ICLD as "information about a client that typically doesn't change over time and is identifiable by its nature. It identifies who clients are, where they are located, what programmes and services they receive and when they receive them. It also includes additional information that tells [MSD] what and when programmes or services were accessed."4

http://www.treasury.govt.nz/statesector/socialinvestment (accessed on 31 March 2017).
 Building Financial Capability Services Guidelines (MSD – Community Investment) January 2017 p19.

https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/community-investment-strategy/about-the-communityinvestment-strategy.html (accessed on 31 March 2017).

Building Financial Capability Services Guidelines (MSD - Community Investment) January 2017 p19.

- 3.3.2 Specifically, MSD began requiring a first tranche of NGOs to provide client demographic information, information about the client's dependents and service level information, for each client that receives the MSD-funded service from mid 2016.⁵
- 3.3.3 MSD's Community Investment Strategy Update 2016⁶ outlines the ICLD policy thus:

IMPROVING DATA COLLECTION

Data collection and information-sharing for better results

Starting from July 2016, we will begin collecting individual client level data from providers⁷. We will do this progressively over the year, so that we are collecting client level data from all providers by July 2017.

Client level data minimum requirements are as follows:

Client	Name, address, gender, date of birth, primary ethnicity, iwi.
Dependents	Name, date of birth, relationship to client ⁸ .
Service	Information Programme/service name, start date and end date.
Level	

Client level data will help us to better understand the history and the needs of clients, and what types of interventions are likely to work. We will then be able to better identify target groups of programme and service users and understand if a programme or service is effective.

As we develop our capability to use this data effectively, we will be able to look across other programmes and services that clients access (funded by other Government agencies) and be better able to understand what programmes and services are attributed to the results we are seeking.

Improving our data collection means we will be able to work with other Government agencies when developing annual investment plans, ensuring that across government we are purchasing a mix of programmes and services that are effective, targeted and provide the results needed for New Zealand's most vulnerable people.

Affected NGOs

3.3.4 MSD funds more than 2,300 NGOs or "social services providers" to deliver around 4,300 contracts supporting children, individuals and families annually, accessed by a very significant number of New Zealanders in need. These contracts are linked to MSD's four service lines – Work and Income, Child, Youth and Family, Family and Community Services, and the Ministry of Youth Development.⁹ Part 8 of the Children Young Persons and their Families Act 1989 provides the authority for MSD to fund community

⁵ NGOs that already have ICLD provisions in their funding contracts are: Family Start, Services in Schools (Social Workers in Schools, Youth Workers in Schools, Multi Agency Support Services in Secondary Schools), Building Financial Capability, Community Finance and Stand for Children's services (Intensive Wrap Around Family Service and Family Therapy Service).

 ⁶ Ministry of Social Development Investing in Services for Outcomes – Community Investment Strategy Update August 2016, p15.
 ⁷ In MSD documents NGOs are described as "service providers" or "providers".

⁸ As the policy has progressed MSD has changed the information requirements. Now dependants' names are not required, instead MSD requires information about the number of dependants and the date of birth of the youngest dependant. Information about the country of birth of the client, and source of referral to the service is also required. See https://www.msd.govt.nz/about-msd-and-our-

work/work-programmes/community-investment-strategy/individual-client-level-data-collection.html (accessed on 31 March 2017). ⁹ https://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/investing-in-services-for-outcomes/investing-in-services-for-outcomes.pdf

services that have a children, young person, family or whanau focus.¹⁰

- 3.3.5 The kinds of services provided by NGOs are diverse. NGOs we communicated with provide services including: budgetary advice, counselling in response to sexual violence or trauma, respite care for children whose families are in distress, settlement support services for refugees and migrants, elder abuse and neglect services, support for people living with HIV, anti-bullying programmes and many more. MSD is in the process of rolling out the ICLD policy for all MSD-funded NGOs.
- 3.3.6 Updated guidance on MSD's website (as at 3 April 2017) says that it is "currently undertaking a scoping exercise which will identify any programmes or services that will not be included. Given the importance of ICLD to a Social Investment approach, there will have to be a compelling reason to exclude a programme or service from these requirements. An example would be programmes that target population groups (such as prevention campaigns) where it is impractical to collect ICLD.^{*11}

How does this differ from the information NGOs currently provide?

- 3.3.7 Prior to the ICLD policy, unless NGO services were being provided as a condition of receiving a benefit, NGOs were only required to report on aggregated client information and the results they had achieved with their clients. This was typically shared with MSD as 'volume based reporting' or case studies.
- 3.3.8 NGOs already collect a range of quite detailed data¹² from their clients for internal use, such as administration, audit and managing cases (92% of survey respondents collect information for these purposes), sharing or coordinating with other service providers (40%) or sharing with MSD or other funders (34%). As such, it is not necessarily the *collection* that NGOs oppose; it is the *mandatory sharing* of this detailed client level data with MSD.

"Internally [client level data] is used for keeping client files, evaluating services, knowing who is using our services in terms of gender, ethnicity etc. We only share client level data with other service providers when they sign consent for us to do so, such as referring the client to another service or co-working with another service that is also involved with the family. We provide anonymised data to MSD and other funders such as number of clients, what services they accessed, how long they were in the service, client feedback on the service they received, evaluating the efficacy of the service, statistics about gender, ethnicity, area people live in etc." (Survey Respondent)

3.3.9 While NGOs collect detailed information on many of their clients already, 44% of survey respondents said that their NGO currently allows clients to access services without having to provide any personal information. Fifty-six percent do not allow the anonymous provision of services.

¹⁰ Sections 403, 406 and 407 enable MSD's CEO to approve funding to community services (NGOs) to fulfil the purposes of the Children Young Persons and their Families Act 1989 – see Appendix B.

¹¹ <u>https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/community-investment-strategy/individual-client-level-data-collection.html (accessed on 31 March 2017).</u>

¹² Our survey respondents collected some or all of the following: name, date of birth, ethnicity, iwi, gender, email, address, phone numbers, marital status, dependents' details, WINZ client numbers, educational background, NHI numbers, income bands, school, church or religious affiliation, next of kin, situational information and others.

Diverse clients

- 3.3.10 MSD-funded NGOs assist a range of clients. Some clients are required to receive an intervention because of a legislative requirement e.g. under Care and Protection Services, Youth Justice Services and some Work and Income clients. Those clients are already known to the Government, may be pre-existing WINZ or CYF clients and are required to attend a programme as a prerequisite for obtaining some kind of government benefit or service.¹³ The Government will already have a large quantity of data about these people and the collection of ICLD is clearly more justifiable for mandated attendees.
- 3.3.11 Other clients include self-referrals seeking the support of community services at the prevention or early intervention stage. The ICLD policy applies equally to those NGOs whose clients are already known to the Government, and those who are not. When asked why MSD requires such detailed information about one-off drop-in individuals seeking support, for example from a budgeting, counselling or advisory service, MSD advised that many individuals will interact with multiple services and that it wanted to test this theory as one of the objectives of the ICLD policy.¹⁴
- 3.3.12 NGOs that primarily offer early intervention services to self-referred clients have said that, long term, their services reduce government spend by enabling people to help themselves early on before problems escalate and serious interventions are required. If such clients are deterred from receiving services they are concerned there will "be a longer term higher cost to government as clients who choose not to seek help will represent later with more serious issues requiring more intensive intervention." (Written submitter)

ICLD in Funding Contracts

- 3.3.13 MSD included ICLD clauses in funding contracts starting with a select group of NGOs for the 2016/2017 financial year.¹⁵ Funding contracts with ICLD clauses continue to be rolled out progressively. Under these contracts, MSD will not fund clients for whom the NGO has not passed on ICLD.¹⁶
- 3.3.14 We understand that contracts with an ICLD requirement have already been signed for some services such as Building Financial Capability services (NGOs offering financial and budgetary advice) and Social Workers in Schools. Other NGOs are still in negotiation with MSD about their contracts and have not begun collecting ICLD.
- 3.3.15 The requirement for NGOs to collect ICLD is included in service specifications which form part of the contractual arrangements between MSD and NGOs. MSD outcome agreements require the NGO service be delivered in accordance with the service specifications. Service specifications "are a living document and may be varied at the discretion of the Ministry"¹⁷ and "form part of the Outcomes Agreement."¹⁸

¹³ See s60GAG of the Social Security Act 1964 – attached in the appendix.

¹⁴ Explained during meeting between MSD and OPC staff 29 March 2017.

¹⁵ NGOs that already have ICLD provisions in their funding contracts are: Family Start, Services in Schools (Social Workers in Schools, Youth Workers in Schools, Multi Agency Support Services in Secondary Schools), Building Financial Capability, Community Finance and Stand for Children's services (Intensive Wrap Around Family Service and Family Therapy Service).

¹⁶ MSD report to Ministers Goodhew and Tolley, Community Investment Strategy: Customer Personal Data Sharing Consent 24 May 2016 para 15 says "It will be mandatory that customers who receive an MSD funded service will be required to consent to share their personal data with other Government agencies." ¹⁷ Social Workers in Schools: Service Specifications dated June 2016, p3.

- 3.3.16 The service specifications include a section entitled Measuring Results and Reporting. This is where MSD details the data that it will collect in order to demonstrate that the service/s are achieving outcomes for individuals and whānau. Reporting includes 'results measures reporting' about quantity and quality of services an NGO is providing as well as ICLD reporting.
- 3.3.17 The provisions that govern ICLD collection for the financial year to 30 June 2017 are detailed as follows:¹⁹

You are required to collect the following client level data for all clients engaged or enrolled in the Service.

A. Demographic data
Primary recipient full name (first, middle, and last name)
Full address, including Suburb/Town
Date of Birth
Ethnicity
Iwi affiliation
Country of birth
Gender
Dependants names and dates of birth (where relevant to the service)²⁰

B. Service specific data

Service/s accessed Start and end dates Results achieved

Reporting client level data to the Ministry

The Ministry is currently developing a tool to enable it to safely collect individual client level data. The Ministry will provide a full training programme to participating providers. Providers are not required to report client level data to the Ministry until this tool is supplied. Once the tool has been supplied, providers will be required to report quarterly as per contractual requirements.

Complying with the Privacy Act

This collection requires both the Ministry and the Provider to ensure that all personal information relating to the Service is kept secure and complies with the Privacy Act 1993. To ensure adherence to privacy best practice, providers are required to notify clients that the client data they are collecting will be shared with the Ministry to be used in anonymised form for evaluation, aggregated summary reporting and research purposes.

3.3.18 ICLD collection is being rolled out in two "phases". The first phase is from 1 July 2016 during which time MSD will be collecting identifiable data but the collected information will not be used in a way that identifies the individual the information is about. Phase two from 1 July 2017 however will see data being collected for identifiable use.²¹

¹⁸ Social Workers in Schools: Service Specifications dated June 2016, p3.

¹⁹ ibid, p24-25.

²⁰ MSD told us on 27 March 2017 in a letter from CEO Brendan Boyle that it has since dropped the requirement for dependants' names.

²¹ MSD document distributed to NGOs on 21 March 2017 *Results for clients using data – information for providers* March 2017.

3.3.19 MSD expects to receive the first set of demographic and service data from select programmes and services (phase one data) in April 2017. All remaining NGOs (except the sexual violence services²²) will have ICLD provisions in their contracts from 1 July 2017 (phase two). MSD will begin receiving phase two data (for identified use) from October 2017.

²² NGOs that are contracted to deliver specialist sexual violence services will still have to collect ICLD for clients receiving MSDfunded services not relating to sexual violence.

4.0 Privacy Impacts

- 4.1 In my view by requiring information to be collected from *all* individuals receiving MSDfunded services MSD's ICLD policy is excessive, disproportionate to Government's legitimate needs and therefore is inconsistent with the information privacy principles.
- 4.2 As the policy currently stands, individual clients are required to share their personal information without any flexibility to opt out, (unless the NGO has other funding sources for that client). As a result there might well be several negative consequences. These include:
 - individuals may choose to stay away from seeking help at all leading to worse outcomes for individuals and society as a whole;
 - individuals may provide incorrect information in order to access help to preserve their privacy – leading to inaccurate or useless data for analysis; and/or
 - NGOs may allow those clients who are reluctant to have their sensitive information given to MSD to access services without providing their personal information – leading to reduced funding and risks to NGOs' long-term viability and the "invisibility" to the system of a significant cohort of individuals in need of support.
- 4.3 All of these risks may lead to MSD receiving skewed or incomplete data which would be counterproductive to MSD's stated aims. These risks will be explored more fully below.

5.0 Deterring individuals from vital social services

5.1 Not being able to access services anonymously may deter people from seeking help

"A lot of the work we do relies on confidentiality and some clients will not share their full stories if they think we may report information to authorities. We need to build trust to fully support our clients, especially those who have complex issues." (Survey respondent)

"Many of these clients have a sense of shame and diffidence about having to get assistance but recognise they need to do something to improve things or regain control. They often do not want other people knowing and certainly do not want to become part of a chain of recording that is accessible to government." (Written submitter)

"Families understandably feel that the reasons they come to our organisation should be confidential. They will be very reluctant to engage if they feel data about them will be shared with any number of Government Departments, many of whom seem to have fairly woeful records when it comes to maintaining confidentiality across such large amounts of information." (Survey respondent)

- 5.1.1 MSD has not given sufficient consideration to the consequences of denying people access to services on the basis of a refusal to supply ICLD. I am concerned that this policy could impede vulnerable people's access to much needed services and worsen already difficult circumstances. There are many legitimate reasons that a person may have for needing help but prefer to forgo it because of the perceived risks associated with passing the information to MSD, for example, a domestic violence victim whose partner or cousin works for MSD. These people may become invisible to the Government.
- 5.1.2 When faced with a client who does not want to share their personal information with MSD, NGOs must either:
 - provide the service and source alternative funding for that client;
 - provide the service unfunded; or
 - not provide the service.
- 5.1.3 Delicate trust-based relationships exist between NGOs and clients. NGOs have told us that always having to request ICLD from clients when offering their services will undermine the trust clients have in the NGO staff and volunteers, and may erode the public trust in the independence of NGOs. NGOs are concerned that vulnerable people will cease reaching out for help if they believe NGOs are acting as agents of the government.

"This is starting to have a police state feel to our democracy – the safety of the women that refuges work with can easily be compromised by their information being available electronically. The threat of only funding an organisation if they report on the clients' names is going to push domestic violence back underground and will affect the safety of the women and children that women's refuges work with." (Written submitter)

"There are already huge discrepancies in the access for Māori to mental health services – to be named and reported on when attending a voluntary service is another barrier that will stop Māori from accessing services at an early stage prior to deterioration that involves hospitalisation. This is not cost effective. No one else has the right to know if you are accessing mental health or refuge services – this should be private for the individual." (Written submitter)

5.1.4 No publicly funded entity should consider itself entitled as of right to continue to receive funding without evidence of improved outcomes to service users. However, it appears from my review that insufficient efforts have been made to identify means by which these aims can be met without the associated risk of disengagement.

5.2 Risks to the long term viability of some services

"Our funding from MSD is based on client numbers. If client consent is withheld and MSD does not fund these clients then it is likely that we will have insufficient funding to continue our service." (Survey respondent)

- 5.2.1 A common theme raised by NGOs was that the ICLD policy raised potential significant risks for the ongoing viability of service delivery.
- 5.2.2 A range of funding models exists among the NGOs we heard from. Some NGOs are fully or almost fully funded by MSD, others are part funded by MSD with additional funding from grants, sponsorship, donations and/or the clients themselves. Regardless of funding, NGOs pride themselves on being able to offer independent, flexible, community-based assistance to those in need. NGOs for whom MSD is the major source of funding will be at greater risk if large numbers of clients refuse to agree to ICLD collection.
- 5.2.3 In order to assess the possible affect of the ICLD policy we asked survey respondents "What impact do you think MSD's new disclosure requirements will have on your NGO's ability to deliver services to its clients?"²³
 - Fifty-five percent of respondents said that the requirements to provide ICLD on their clients would have a significant or major impact on their ability to deliver services with some or all affected services having to be reduced or completely withdrawn;
 - Three quarters of respondents who provided written comments thought the changes would have a negative impact on either their clients, or the relationship of trust

²³ Respondents could select from the following: minor – business will continue as usual; some impact – affected services will have to be modified but can still be delivered; significant impact – some affected services will have to be withdrawn or reduced as a direct result; or major impact – affected services will no longer be able to be delivered. Respondents also had the option of providing a written comment.

between them and their clients;

- Eleven percent of respondents said that the policy would have only a minor impact with business continuing as usual; and
- Thirty-four percent said the policy would have some impact: services would have to be modified but could still be delivered.
- 5.2.4 While some NGOs have indicated they will continue to offer anonymous services to people with legitimate concerns about ICLD (even in the absence of MSD funding for those clients), other providers do not have the financial resources to do this. Eighty-one percent of respondents said they would continue to offer services to clients who did not consent to their information being shared even without MSD funding. A significant number of comments noted that this would make it difficult or impossible to cover their expenses and achieve contractual requirements for client numbers.
- 5.2.5 An NGO reported that, where the ICLD collection policy has already been rolled out, up to 50% of clients have refused to agree to their personal information being shared with MSD.²⁴
- 5.2.6 The NGO that reported this has continued to offer services confidentially to those who refuse to share their data. However, as a result of client resistance to ICLD, the overall number of clients served will not be accurately reflected in the information given to MSD instead it will look like fewer clients have been supported than previously.²⁵
- 5.2.7 That NGO is concerned that it will not be able to meet its key performance indicators and it will look to MSD like the NGO's overall output is diminished. NGOs are concerned that MSD will use the ICLD policy to undervalue their contribution and, over time, that their ongoing existence may be threatened. Because funding is limited to only those clients who agree to provide ICLD, NGOs that continue to offer services for those who decline consent will need to find alternative funding sources for those clients.
- 5.2.8 The survival or viability of a given NGO or NGOs as a means of delivering Government funded support is a matter of public policy which is not within my jurisdiction. However, allowing for flexibility in the scope of the policy (e.g. through an opt-out) would reduce risks to NGOs' operational viability caused by potentially significant funding if, as predicted, large numbers of clients refuse to share their information with MSD.
- 5.2.9 I have seen little or no analysis of the impact of this policy on the Government's ability to understand the size, scope and efficacy of practical interventions. Keeping information confidential might in fact be the defining element of the success of a particular programme or intervention. Under a system which excludes these services, Government will be denied that information.

"We will need to seek alternative funding streams for those clients who choose for their personal information to remain private. We already seek alternative funding streams in order to provide our services and know this will be incredibly difficult in the current climate." (Survey respondent)

²⁴ Oral feedback given to the Privacy Commissioner - NGO engagement meeting at the Office of the Privacy Commissioner, 15 February 2017.

²⁵ MSD told my staff on 29 March 2017 that NGOs will continue to provide volume based reporting to MSD so theoretically MSD would be able to get a picture of the total number of clients helped vis-à-vis the number about whom the NGO has provided ICLD.

"We would also like MSD to consider the administrative and financial impact of these changes when negotiating contracts. Our sector has not seen any significant increase in funding for over a decade and these costs have to be offset with a reduction of our frontline staff." (Survey respondent)

5.3 Inaccurate, ineffectual or incomplete data

- 5.3.1 In discussions with MSD²⁶ my staff recommended that MSD allow clients who object to having their ICLD passed on to opt-out of this requirement, with no funding impact for that individual. During that meeting my staff suggested that, in the absence of any identity verification requirement and without an opt-out, there was a perverse incentive for individuals to provide false data. This would reduce the accuracy and usefulness of the data MSD collected.
- 5.3.2 My view is that if MSD were to build some flexibility into the ICLD policy to allow an optout, the data would be more accurate and useful for the stated purpose. Information about what proportion of clients opt out, in itself, could give MSD useful insights into individual trust in the ICLD policy. MSD could identify cohort trends for example if 80% of family violence clients ask to opt out, or Hawkes Bay based clients have a significantly lower opt-out rate than other centres – this information may assist MSD's policy development.
- 5.3.3 For those services where a high proportion of clients have refused consent or have indicated they will refuse consent, MSD may be receiving an incomplete picture of the value of the service, the numbers of clients helped and the results achieved.
- 5.3.4 In my view, MSD needs to think about the consequences for its wider policy objectives if NGOs' clients do not wish to share their information. If NGOs are able to source independent funding, certain clients, cohorts, or whole services may become invisible to MSD. This risk, combined with the possibility that some individuals stop accessing services altogether, may skew MSDs data and its view of the sector overall. Poor or patchy data will be counterproductive to MSD's stated aims.
- 5.3.5 Without flexibility in the application of the ICLD policy, MSD would receive a skewed sample of only those clients that are prepared to have their personal information shared and on-shared, or of clients who have not had the policy sufficiently explained for them to understand the consequences of ICLD collection.

"Most of our clients already deal with government services like WINZ and feel very vulnerable around how much information needs to be given to them but realise they have no choice. If the NGOs start putting this condition on them as part of the service they will actively disengage rather than accept the support." (Survey respondent)

²⁶ OPC meeting note of discussion between OPC and MSD staff 29 November 2016.

6.0 The purpose for collecting ICLD is unclear

6.1 Purpose

"MSD has not been clear how they will use the identified data. Could it end up with the client being sanctioned by MSD from the providers [NGO's] information supplied? Providers aren't here to be MSD's police men and women." (Survey respondent)

- 6.1.1 Purpose is a central consideration when collecting personal information. The Privacy Act lays out twelve information privacy principles²⁷ that govern the lifecycle of personal information. Principle 1 of the Privacy Act requires an agency to only collect information for lawful purposes that are connected to its functions or activities where collection is necessary for that purpose. The operation of many of the other principles flows from this starting point. For example, when collecting information agencies must tell people what purpose they are collecting it for (principle 3), and information can then only be used (principle 10) or disclosed (principle 11) in line with this original purpose unless an exception applies.
- 6.1.2 It is fundamental to people's right to privacy that, when providing information about themselves, individuals know why the information is being collected and what is it going to be used for.
- 6.1.3 Through this inquiry NGOs have reported that MSD has not clearly articulated its purpose for collecting ICLD. I share that experience. MSD has said that information will be used in two phases:²⁸ Phase one is for de-identified research and analysis. Phase two will see information used in an identifiable form for as yet undefined purposes that may include profiling.
- 6.1.4 MSD's purpose for collecting ICLD and the potential uses for it have been explained differently in different policy documents as the ICLD policy progressed. In March 2016, MSD reported to Minister Tolley that "*by collecting information on clients, and then assessing the effectiveness of different providers and programmes in achieving results for clients, we will have the basis of a system that can:*
 - Track results for individual clients (and cohorts of clients) in a meaningful way first through the Results Measurement Framework, and eventually through data matching.
 - Build an evidence base about who is accessing our services, where, and what works for different types of client cohorts.
 - Enable effective practice to spread, and foster innovative new solutions through the shared measurement of results for different client cohorts. "29

²⁷ These are contained in s6 of the Privacy Act 1993 <u>http://legislation.govt.nz/act/public/1993/0028/latest/DLM297038.html</u> (accessed on 31 March 2017).

²⁸ Building Financial Capability Services Guidelines (MSD – Community Investment) January 2017 p20.

²⁹ Report to Minister Tolley Community Investment Strategy: Contracting changes from 1 July 2016 paragraph 22, p5.

- 6.1.5 In May 2016, MSD reported to Ministers Tolley and Goodhew that "Collecting and sharing personal data about customers is an essential part of the [Community Investment] Strategy to improve the efficiency and effectiveness of social service investments."³⁰
- 6.1.6 MSD advice to Ministers has indicated that ICLD will be matched against Ministry of Health, Ministry of Education and Ministry of Justice data held about those clients.³¹ MSD has not explained what the matched data will be used for and whether the ICLD will be further shared with other government departments in time.
- 6.1.7 In June 2016, MSD reported to Ministers that it intends "to be able to target services to identifiable persons from July 2017."³² That report went on to say "by July 2017, the Ministry intends to put in place the appropriate tools and processes to be able to **share identifiable client level data across MSD service lines or across agencies** for the purpose of targeting **any** intervention, or provision of a service to an identifiable individual [emphasis added]." Because MSD will collect individual-level data and share and compare this against other government data held about those specific individuals, MSD will be able to paint detailed pictures of specific individuals' interactions with government and their social needs.
- 6.1.8 In response to NGO questions at MSD's NGO engagement meeting in December 2016, MSD conceded that potential future uses of ICLD could include profiling or predictive modelling to "create coefficients of likelihood" of certain outcomes for individuals.³³ It is not clear whether this is intended as a tool to justify state intervention in an identified individual's life, or to support wider research.

"We are extremely concerned about the ethics of collecting identifiable client data for use in individual tracking, as intended by MSD." (Written submitter)

- 6.1.9 The specific uses and the flow of information once MSD has received ICLD have not been well defined. MSD says that collecting ICLD will help it "understand who's receiving the programmes and services [it] fund[s] and what impacts those programmes and services are having on them."³⁴ It has articulated a high level view of its purpose for collecting ICLD and what it hopes to achieve as it integrates ICLD with its own and other agencies' data sets, including being able to see:³⁵
 - which client groups access what type of services;
 - the extent to which clients are accessing services funded by other agencies; and
 - the type of service mix clients are accessing, and whether there is any duplication.

 ³⁰ MSD report to Ministers Tolley and Goodhew *Community Investment Strategy: Customer Personal Data Sharing Consent* 24 May 2016 p3.
 ³¹ Report to Hon Jo Goodhew, Associate Minister for Social Development and Hon Anne Tolley Minister for Social Development, and Hon A

³¹ Report to Hon Jo Goodhew, Associate Minister for Social Development and Hon Anne Tolley Minister for Social Development, Status update on Community Investment's collection of Individual Client Level Data and Information Communications Technology solutions, 1 December 2016 p4 para 15.

³² Report to Ministers Tolley and Goodhew, *The collection and use of Community Investment client level data*, 24 June 2016, p1.

³³ OPC File note: MSD-NGO Workshop – Client Level Data 13 December St John's Church, Wellington p2.

³⁴ Building Financial Capability Services Guidelines (MSD – Community Investment) January 2017 p19.

³⁵ Email from Peter Galvin, General Manager, Community Outcomes and Services, MSD to ICLD workshop attendees on 22 December 2016.

- 6.1.10 Once ICLD has been integrated with other data sets, and client results data is included MSD expects that it will be possible to see:
 - the results providers are achieving with clients, and whether these are different across different types of clients, e.g. age, ethnicity or geographical location;
 - whether particular providers seem to be achieving better results for certain types of clients; and
 - whether the results achieved with clients can be linked to changes in results that are better than what would have been expected.
- 6.1.11 The ambiguity about the specific use of information once it has been analysed, particularly the question of whether any adverse action might be taken against an individual based on their ICLD, means that MSD has not clearly articulated the purpose for which this personal information is being collected. It is not clear how the information about individuals, once matched with other information will actually be analysed and used and the outcomes for the individuals the information pertains to.

6.2 It is not clear whether the universal collection of ICLD meets the necessity test in privacy principle 1

- 6.2.1 Principle 1 requires that agencies may only collect information that is *necessary* for their lawful purpose for collection. The collection of ICLD does not appear to be necessary for the purpose of assessing the effectiveness of services. Because the purpose of collection is not clear, as discussed above, it is also difficult to assess whether the necessity test is met.
- 6.2.2 A key consideration is MSD's collection of ICLD from *every* individual receiving a service. Blanket collection of ICLD is a central part of the contractual changes, but it is not clear that collecting information about 100% of service users is a justified and proportionate way for MSD to meet its objectives of assessing the efficacy of programmes or the combination of determinants of different outcomes.
- 6.2.3 There will always be situations where people should be able to access services anonymously, particularly where necessary to protect individual well-being or safety. Sixty-one percent of survey respondents said they would support the ICLD collection policy if MSD funding continued for clients who opt out of sharing their personal information. However, 39% said they would not support the policy even if funding continued for those clients who opt out of sharing.
- 6.2.4 The purpose of collection, in phase one at least, is primarily aimed at aggregate understanding of service delivery, improved financial accountability and accountability for outcomes. I am not convinced that blanket collection of ICLD is necessary for that purpose to be achieved. Collecting anonymous information or information from a large subset of service users (e.g.80%) would likely accomplish MSD's goals and such it is difficult to argue that ICLD collection from all clients is necessary in terms of principle 1.
- 6.2.5 If these goals can be met adequately by an alternative and less privacy intrusive means such as permitting individuals to decline to provide their information when they consider it sensitive, it follows that the blanket collection is not necessary and the requirements of principle 1 are not met.

"Rape and sexual abuse is a very personal and sensitive matter – our survivors would rather not have information like this available to people unknown to them." (Survey respondent)

6.2.6 A significant challenge that NGOs voice about the ICLD policy is that MSD has been unwilling or unable to clearly explain how the data will be used once it is passed to MSD. The flow of information, why ICLD is necessary to achieve the policy goals of effectively delivering and assessing services, and why this information is required from 100% of clients in an identifiable form have not been explained.

> "There is a lack of detail about how this level of data will contribute to MSD's understanding of the effectiveness of the various services and programmes it funds." (Written submitter)

6.2.7 NGOs are not necessarily concerned that *new* information needs to be collected, (although in some cases it will, particularly for those NGOs who provide anonymous services). The bigger issue is that NGOs fail to understand or support *MSD's need to* see this information and its purposes for using it.

"We know that having to share and collect information is an important factor at times in the work that we do. Government has yet to tell us why they require ICLD, how it will be used and by whom and how the information will be kept safe." (Written submitter)

6.2.8 NGOs generally support MSD's need to analyse the effectiveness of service delivery and to assess client results. A number of NGOs told me that they collect thorough data and are willing to share this with MSD so that MSD can assess cohort results by region, ethnicity, or age, and to allow MSD to compare service results across NGO providers. At the same time NGOs do not understand how clients' names, addresses, birthdates and children's details are necessary or relevant for this kind of analysis and are, in the main, uncomfortable sharing this.

"Our gathered data is used heavily by government departments as we are the largest organisation that collects the relevant information to understand the status of sections of New Zealand's residents. NO names and addresses are forwarded on though!" (Survey respondent)

"We provide anonymised data to MSD and other funders such as numbers of clients, what services they accessed, how long they were in the service, client feedback on the service they received, evaluating the efficacy of the service, statistics about gender, ethnicity, area people live in etc." (Survey respondent)

6.3 Unclear purpose for collection makes it difficult for NGOs to comply with privacy principle 3

- 6.3.1 Principle 3 requires that when agencies collect personal information, they must inform the individual of why their information is being collected and what it will be used for. Because the purpose for the collection of ICLD, and how MSD intends to use this information in the future, is not clear, it is difficult for NGOs to comply with principle 3 when collecting information from their clients.
- 6.3.2 NGOs are concerned that collecting personal information for an insufficiently defined purpose breaches the Privacy Act. Without a complete picture of the use for which the ICLD is being collected and the intended recipients of that information, NGO representatives believe that they are unable to comply with principle 3.

"A lot will depend on how I could explain about how the information would be used and I am not sure about that myself at the moment. I don't really know how I would manage this." (Survey respondent)

- 6.3.3 An agency does not need to comply with principle 3 where any of the exceptions in principle 3(4) apply. Relevant exceptions are where:
 - non-compliance would not prejudice the interests of the individual concerned;
 - compliance would prejudice the purpose of collection;
 - compliance is not reasonably practicable; and
 - the information will be used in a form where the individual concerned is not identified.
- 6.3.4 This obligation of transparency rests on the agency collecting the ICLD directly from the individual client, in this case the NGO as the collecting agency.
- 6.3.5 Although MSD is requiring NGOs to collect information on its behalf, MSD does not have a legal obligation to comply with principle 3 or concern itself with how NGOs are collecting the information. MSD does however need to be clear about its purpose in collecting ICLD so NGOs can pass this on to their clients and fulfil their legal obligation under principle 3.
- 6.3.6 The NGOs are collecting information directly from their clients and must satisfy each aspect of principle 3 by communicating:
 - a. The fact that information is being collected: The NGOs can satisfy this requirement.
 - b. The purpose of collection: To the extent that MSD's purpose is not clear, e.g. the ambiguity around how identified data may come to be used to make decisions about the individuals concerned from 1 July 2017, NGOs may not be able to comply with principle 3 because they will be unable to clearly and accurately communicate the purpose for which the ICLD is to be used. While a statement from an NGO to a service user "we are collecting this information to give to MSD" may be a bare minimum legal compliance, it would be so general as to defeat the purpose of the requirement.

- c. **The intended recipients of the information:** In the absence of a clear and specific purpose, and since MSD has not specified the full range of potential agencies that will receive or have access to ICLD, NGOs will not be able to satisfy this aspect of their obligations under principle 3.
- d. **The name and address of the agencies collecting and holding the information**: These details are publicly available and can be easily communicated.
- e. Whether the collection is legally mandatory or voluntary and any consequences for the individual for not providing it: Collection is not required by law, but NGOs will need to inform their clients that a possible consequence of not providing their information is that the service may not be available to them.
- f. Legal access and correction rights: The NGOs would have no apparent issues satisfying this obligation.
- 6.3.7 Not only has MSD failed to adequately explain the range of purposes the ICLD will be put to, it has not adequately explained what the information will *not* be used for³⁶. Assurances about how the information will not be used, in particular whether ICLD would contribute to any adverse action being taken against any individual, are equally important in terms of building trust and managing risk.

"If MSD knows my budget is so tight, will they take my children off me?" (Oral submission – NGO conveying client sentiment)

6.4 Unclear purpose at the time of collection may create future problems under privacy principle 8

- 6.4.1 Privacy principle 8 requires that agencies take reasonable steps to ensure, having regard to the purpose for which it is to be used, that personal information is up to date, complete, relevant and not misleading before using it. What constitutes reasonable steps is dependent on a number of factors, particularly the potential consequences of inaccuracy.
- 6.4.2 MSD is requiring NGOs to collect and pass on ICLD about their clients. Depending on the use to which the information will be put, there are different standards of accuracy that would be needed for this information. For example, where the information is to be used to match service users across services for aggregate analysis, a certain number of false matches may be expected, and statistical techniques can be used to take this into account. The steps needed to ensure accuracy may therefore be lower. A higher standard would apply where the information is to be used to directly affect the individuals concerned.
- 6.4.3 In the case of the collection of ICLD from NGOs, it is important to understand the future uses of information at the point of collection, so that appropriate steps can be built in to ensure the information is sufficiently accurate. Information that is fit for the purpose of aggregate assessment of service provision and outcome assessment is not necessarily adequate for operational uses such as risk prevention and direct intervention.

³⁶ After sharing an early draft of this report with MSD, MSD provided additional information to NGOs about the ICLD policy which stated that "we are not going to be using the data for anything outside of the stated purpose of gathering this data to make sure that people who need help are being matched to the right services and that the services are actually producing results for the clients."

- 6.4.4 There is a risk that if MSD gathers information in a way which means it cannot have confidence in the accuracy of the information, the uses to which this information can be put in future will be limited. To my knowledge, MSD has not provided any guidance to NGOs on the steps they need to take to verify that ICLD is accurate for MSD's purposes. For example, MSD officials have informed my staff that NGOs will not be required to confirm client's identity (i.e. to ensure that people are not giving false names) when they enrol for services. It is possible to foresee a situation where a person concerned for their privacy accesses services using a family member's name. It is unclear whether MSD has considered the impact of this risk.
- 6.4.5 A failure to take appropriate steps to verify the accuracy of information collected by NGOs would raise issues under principle 8 if the information was subsequently used to make decisions which directly impact on people's lives.
- 6.4.6 NGOs may consider that taking measures to ensure the accuracy of the data they are collecting on MSD's behalf would be inconsistent with the NGO-client trust relationship. NGOs are likely to have strong incentives to not drive vulnerable clients away by intrusive questioning; this may lead to passing on information that is, or appears likely to be incorrect, which could raise issues under principle 8.

6.5 Unclear purpose creates problems for privacy principle 10

- 6.5.1 Privacy principle 10 requires agencies to only use personal information for the purposes for which they obtained it, unless one of the exceptions to the principle applies. The effect of principle 10 is to ensure agencies are accountable for their actions when collecting information by prohibiting them from 'repurposing' information. This transparency and certainty fosters informational autonomy, and increases public trust in how government handles personal information.
- 6.5.2 MSD's stated purpose for collection is to help MSD "understand who is using the programmes and services [it] fund[s] and what impact those programmes and services are having".³⁷ At this stage, when processes for information collection and use are still being developed, and information has not begun to be transferred to MSD, it is not possible to assess whether MSD has improperly used ICLD for purposes beyond the stated ones.
- 6.5.3 However there is a more foundational problem, which is that the vagueness of the stated purposes makes it difficult for individuals and NGOs to assess whether principle 10 is being complied with. This vagueness indirectly damages MSD's accountability for the information it is collecting and holding, and increases the risk that a breach of principle 10 will occur or be perceived to have occurred.
- 6.5.4 Similar potential issues apply if the vagueness of MSD's purpose means that it is difficult for NGOs to confirm that the stated purpose of collection is being subsequently adhered to.
- 6.5.5 A relevant consideration for NGOs is that they are obliged to rely on MSD to hold, use and disclose information in line with its stated purposes, but are likely to incur any damage to trust relationships *themselves* if information is repurposed. For instance, if MSD uses information improperly or for an as yet undefined purpose this will damage vital trust relationships between NGOs and clients.

³⁷ <u>https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/community-investment-strategy/individual-client-level-data-collection.html (accessed on 31 March 2017).</u>

7.0 ICLD policy process was poorly developed

7.1 Policy development process

"We believe it is essential that the people whose private information will be collected and shared under this new funding requirement get an opportunity to express their feelings and concerns, and overwhelmingly their voice is shouting, "Keep my private details private to the organisation I'm giving them to".

(Written submitter who independently polled 26, 500 current and former beneficiaries on client data being shared with MSD)

- 7.1.1 I have concerns with the process MSD has followed in implementing the ICLD policy. I would expect such a significant change of policy and process to have systematically considered the privacy implications involved before implementation. Such a consideration would have involved an identification and evaluation of the Government's legitimate aims and the range of alternative means of meeting these, ranked with reference to relative efficacy, impact on services and effect on individuals. In addition, adequate privacy safeguards had not been developed in advance of implementation.
- 7.1.2 MSD provided me with documents showing a progression of ICLD policy advice sent to the Minister of Social Development and Associate Minister of Social Development from 8 March 2016 continuing through to the present.
- 7.1.3 In a report to Associate Minister Goodhew dated 24 May 2016 official advice included the following:
 - sharing of a client's service history from one service provider to another (on-sharing) could only be done with the consent of the client;
 - clients receiving sensitive services (such as victims of sexual violence) would be able to opt-out of sharing their names and addresses;
 - high level aggregated customer data would be anonymised to inform research and statistical purposes;
 - an acknowledgment of the legal and ethical risks that MSD would need to manage "At the time of obtaining a customer's consent we will clearly identify the data that we are collecting, what the data may be used for and who will have access to it, with an appropriate degree of specificity",³⁸
 - MSD had prepared standard consent forms for use by NGOs that did not have suitable consent forms;³⁹
 - ICLD would be shared with the client, the case worker, the service provider, any subsequent provider the client consents to sharing with, MSD Programme Managers and other Government agencies with cross partnerships; and

³⁸ MSD report to Ministers Goodhew and Tolley, *Community Investment Strategy: Customer Personal Data Sharing Consent* 24 May 2016 para 26.

³⁹ An MSD prepared information sharing client consent form appended to an internal MSD memo on 8 March 2016 included an understanding that the client's "personal details will not be identifiable in any reports provided to the Ministry".

- service delivery staff analysing the data, other Government agencies and service providers, Ministers, the media and Statistics New Zealand would only see aggregated statistical data (i.e. the identifiable individual data would not be seen).
- 7.1.4 MSD first consulted my staff on this policy in June 2016.
- 7.1.5 In an aide-mémoire dated 29 September 2016, MSD advised Associate Minister Goodhew that it was "working on a Privacy Impact Assessment (PIA) to identify any potential privacy risks and mitigations." We have not seen a PIA, and MSD confirmed that a PIA has not been completed as at 23 March 2017.
- 7.1.6 As the policy developed, references to an opt-out for clients receiving sensitive services dropped off⁴⁰ and NGOs were expected to draft their own consent forms with minimal guidance from MSD. By December 2016 it was clear that the policy would require ICLD to be collected in an identifiable way for all service types. MSD also moved away from anonymised data for research purposes to identifiable data for sharing and matching with other agencies. MSD did not advise service providers and clients with an appropriate degree of specificity what the collected data would be used for and who would have access to it.
- 7.1.7 It is unclear from the documents MSD gave us whether the changes in the policy detail occurred in response to explicit Ministerial direction or whether official advice changed. Nor is it clear on what basis these changes were decided. I have not enquired as to the reasons for the purposes of this inquiry only the fact of the change is relevant.
- 7.1.8 MSD plans to have a final set of standards in place no later than 31 March 2017 to implement phase two use of identifiable data on 1 July 2017. MSD is also working to measure service results, and trialling 'results based contracting'.⁴¹ MSD requires all services to have results reporting in place by 1 July 2018.

"When it becomes a matter of continuing to have a presence in our community we may be forced to limit the number of non-consenting clients we take on." (Survey respondent)

7.1.9 The ICLD policy is being rolled out at a time of change in how the Government intends to deliver its own services – with the new Ministry for Vulnerable Children, Oranga Tamariki in place from 1 April. The Children, Young Persons, and Their Families (Oranga Tamariki) Legislation Bill⁴² includes mandatory information sharing requirements and the Family Violence legislation currently being developed includes a presumption of information sharing.⁴³ In this context, NGOs can have no confidence that ICLD will only be used for research and analysis.

⁴⁰ After receiving an early draft of this report, MSD contacted providers of sexual violence support services informing them of a 12 month ICLD exemption while security and storage processes are worked through.

⁴¹ Where results are set at the contract level rather than to the programme or services level.

⁴² This bill was introduced to parliament on 8 December 2016 and at the time of writing is being considered by the Social Services Select Committee, see <u>http://www.legislation.govt.nz/bill/government/2016/0224/latest/DLM7064516.html</u>

⁴³ The Ministry of Justice Cabinet paper containing the policy decisions regarding information sharing for family violence can be seen here: <u>https://www.justice.govt.nz/assets/Documents/Publications/fv-reform-paper-1-context-and-supporting-integrated-responses2.pdf</u>

- 7.1.10 There are inconsistencies in approach across these new schemes. The information sharing powers in both the proposed Family Violence legislation and the Oranga Tamariki Bill will be subject to exceptions. The ICLD policy has no exceptions. An NGO providing support to a family fleeing violence would be able to give affect to their client's wish not to share information in some circumstances under Oranga Tamariki or Family Violence legislation, but the funding contract (in its current form) would in effect override the discretion afforded by the proposed legislation. For example, the Oranga Tamariki Bill includes a presumption of information sharing unless to do so would not be in the best interests of the child. Under the ICLD policy, even if an NGO believed that passing ICLD on to MSD would not be in the best interests of a child, it would be forced to do so, or would have to go without funding.
- 7.1.11 NGOs are concerned with the speed at which this policy has been progressed. At MSD's NGO engagement meeting in December 2016, NGOs said that timeframes were too tight for adequate privacy processes to be followed.

"There's a brutal timeframe on this." ⁴⁴ (Oral NGO comment)

7.2 MSD approach to including ICLD in funding contracts

- 7.2.1 My staff met with an NGO representative to discuss the process MSD had followed to include ICLD collection in their funding contracts. The NGO described the process as "appalling".
- 7.2.2 When ICLD collection was first mentioned to the NGO as a 'heads up' in 2016 there was little detail around what information MSD would be collecting and for what purpose. The NGO opposed ICLD collection, questioned MSD about the purpose and detail of the requirements and requested MSD provide consent forms suitable for collecting ICLD from clients. These were not forthcoming. In August 2016 (at which point the NGO was funding its services out of its reserves), the NGO signed the overarching outcomes agreement. This document covers the agreed price of services, outcomes to be achieved, performance measures, payment and reporting requirements. The integrated outcomes agreement did not include ICLD provisions.
- 7.2.3 When MSD counter-signed and returned the outcomes agreement to the NGO, MSD attached new service specifications that included ICLD collection provisions. At the time of signing the outcomes agreement the NGO had not seen these finalised service specifications, as the Ministry had been negotiating them internally and with the Minister. Although the service specifications were dated June 2016, the NGO was not provided with them until late August. The NGO felt that by altering the service specifications to include ICLD, and attaching them to the countersigned outcomes agreement without giving the NGO an opportunity to review or challenge the ICLD provisions, MSD had acted in bad faith. The NGO also questioned the appropriateness of the contract being made up of both the outcomes agreement and service specifications when MSD is able to vary the service specifications at its own discretion. Such a provision makes it difficult, if not impossible, for an NGO to meet its legal obligations to disclose the

⁴⁴ Comment made at MSD-NGO engagement workshop 13 December 2016 – source: OPC staff meeting note.

purpose of collection to clients as described above (at paragraph 6.3.1).

"Often people with limited resources feel they're expected to have less right to a private life - it feels like the Government picking on poor people because they can." (Oral NGO comment)

- 7.2.4 Other NGO representatives confirm that ICLD clauses appearing in funding contracts for the 2016/2017 financial year came as a surprise without explanatory supporting information.
- 7.2.5 The range of uncertainties means that some NGOs are reluctant or unwilling to sign funding contracts.⁴⁵ Due to NGO opposition there are currently delays in finalising contracts for some services. Other NGOs confirmed they too were operating out of their financial reserves.
- 7.2.6 As well as questioning the rapid roll out of the ICLD requirements in contracts, NGOs have said that MSD has not adequately communicated with them and their clients about the policy, nor has it negotiated in good faith contracts that include ICLD.

7.3 Lack of trust

7.3.1 MSD has said that it is aware of the importance of trust in dealing with clients:

"With regard to work being undertaken around the collation of individual client level data, the Ministry's Privacy Strategy articulates the importance of privacy to gain our clients' trust in managing their information. Trust is critically important if we want to leverage the value of information to enable better outcomes for New Zealanders." 46 (MSD)

7.3.2 Despite MSD's stated belief, it risks achieving the opposite. NGOs have told us that an absence of trust has underpinned the ICLD policy. Mistrust is based on MSD's historical handling of personal information, the risk of ICLD being used for a different purpose in the future, and the inherent security difficulties agencies face in ensuring unauthorised staff do not access sensitive information.

> "Trust is also an issue. Trust is a feature in the relationship between client and service providers and affects client perception of MSD as a recipient. holder or user of information. [ICLD collection] will impact on client trust, it will deter some from accessing services and those who do access services will be reluctant to fully disclose." (Survey respondent)

⁴⁵ See recent media reporting: <u>http://www.radionz.co.nz/news/national/326040/rape-crisis-will-risk-funding-to-keep-data-private</u> and http://www.stuff.co.nz/timaru-herald/news/90011360/budget-advisory-refuses-to-send-client-information-to-government (accessed on 31 March 2017). ⁴⁶ Letter from MSD CEO Brendan Boyle, to the Privacy Commissioner dated 3 March 2017.

"Client whānau trust is huge. If whānau know you're going to share their personal information with other departments or possibly be [sic] public they will not engage or trust us to support them." (Survey respondent)

"There is a generalised suspicion amongst our clients that data will be used in a way that may adversely affect their access to benefits and ultimately their lives. Potentially this could become the stick and not the carrot. We believe that this in turn could entrench benefit dependency." (Written submitter)

"Service providers will be required to trust MSD (despite its long record of public and private malfeasance and IT and procedural screw-ups) to take the raw identifiable CLD and massage it into some unidentifiable aggregate form, while keeping the raw CLD perpetually private, even internally. I for one do not trust them that far, especially since MSD's policy on securing the raw CLD could be changed at any time." (Written submitter)

7.4 Poor process raises concerns under privacy principle 4

- 7.4.1 Privacy principle 4 regulates how agencies can collect personal information, rather than what they can collect. It obliges an agency to not collect information by means that are unlawful or, having regards to the circumstances of the case, are unfair or unreasonably intrusive.
- 7.4.2 MSD is collecting ICLD through NGOs from clients with sensitive personal circumstances some of whom may have strong reasons to keep their identity unknown. It is using the withdrawal of funding as a lever to compel provision of this information in the face of clearly articulated protest from the NGOs concerned and their clients.
- 7.4.3 The Ministry's use of contractual funding constraints to require NGOs to collect information on its behalf does not amount to an unlawful method of collection under principle 4. However, NGOs have made representations that MSD is effectively compelling the collection of ICLD from service users, who are seeking help for deeply sensitive personal issues such as domestic abuse, financial crisis and other trauma, and that this might amount to an unfair and unreasonably intrusive method of collection if a less intrusive method of collection exists and could practically be employed.

"Male survivors of sexual abuse wish their issues to be treated with total confidentiality. Survivors were abused as a result of loss of control of their situation. Sharing information is seen as a further loss of control. MSD shows a total lack of understanding of the need for trust and confidentiality in this sensitive support environment." (Survey respondent)

7.4.4 While I acknowledge NGOs concerns, on balance it does not appear that MSD's method of collection meets the level of unfairness or unreasonable intrusion set in principle 4, although such a finding might be available to the Human Rights Review Tribunal if an aggrieved individual were to suffer some harm and pursue a complaint.

7.4.5 NGOs argue that because funding for individual clients is limited to only those clients who share ICLD with MSD, there is an appearance of coercion about this policy.

"We believe our clients have a right to privacy when it comes to their personal affairs. The fact that they need support from us should not mean they have to provide their identity to MSD. We would only accept an opt-in provision, where clients would only supply information if they wanted to, without any level of coercion, and knowing that the information could not be used in a harmful way." (Survey respondent)

Consent

- 7.4.6 Many NGOs provide services on the basis of consent. Some MSD-funded NGOs currently offer services on a completely confidential basis, with no compulsory personal details required prior to a client receiving a service. When the ICLD policy is rolled out for these services, this practice will no longer be possible within government funding. These NGOs will need to have other funding sources to absorb the costs or choose not provide the service.
- 7.4.7 NGOs have been advised by MSD that they need to inform their clients that ICLD will be shared with MSD. NGOs are also aware of the delicate relationship that exists with some clients. These factors mean that some NGOs are choosing to seek written consent from clients before they collect ICLD and share it with MSD.
- 7.4.8 Despite requests from some NGOs, MSD did not provide model consent forms, or ICLD purpose statements for sharing with clients. I am pleased to note however that after commencing this inquiry, MSD acknowledged the need for better and clearer communication with NGOs and clients. On 21 March 2017, MSD emailed out supplementary information on the collection of ICLD to NGOs, including a one page document for showing to clients entitled *Sharing information to help the Ministry of Social Development improve programmes and services.* However this document does not provide clarity on the purpose for collection.

"[We are] very concerned about the ability of our clients to give informed consent - partly understanding the risks they are taking about information being used for purposes other than those for which it was provided but also partly the concern they have about the impact declining to provide the info will have on the agency (which makes some feel they should agree out of appreciation for the service, even though they wouldn't freely choose to)." (Written submitter)

"Most of our clients are children, some as young as 7 years old. They are participating in a violence prevention/early intervention programme. Presumably parental permission will be required for their children's information to be shared with us and with MSD – and the very parents whose children can most benefit from the programme (e. g. parents from violent or abusive families, parents whose children's safety is most at risk) are the least likely to give this permission." (Survey respondent)

7.5 MSD has not adequately considered professional codes of ethics

- 7.5.1 A number of NGO representatives that spoke to us are covered by their own professional ethical codes. These include the registered social workers code of conduct and privacy expectations,47 the Health and Disability Code of Rights,48 New Zealand Association of Counsellors' code of ethics,⁴⁹ and the code of ethics for psychologists working in New Zealand.⁵⁰ These codes detail professional standards of behaviour, integrity and conduct that apply to professionals acting in these sectors. The codes include confidentiality and privacy consideration and, in the case of psychologists impose an obligation on the practitioner to gain informed consent of the client receiving the service. NGOs also cited obligations under the Victims Rights Act 2002.⁵¹ Appendix C includes extracts from relevant professional codes of ethics.
- 7.5.2 Extract from Code of Ethics for Psychologists working in Aotearoa New Zealand:

1. 6. Privacy and Confidentiality:

Value Statement:

Psychologists recognise and promote persons' and peoples' rights to privacy. They also recognise that there is a duty to disclose to appropriate people real threats to the safety of individuals and the public.

7.5.3 In the case of the New Zealand Citizens Advice Bureau, the confidentiality of client personal identification details is a core principle of its Code of Ethics. As such, for MSDfunded services operating within the CAB's code, collecting and sharing ICLD puts those service providers in breach of their own ethical standards.

> "Our budget service is staffed largely by volunteers. They should not be pressured to seek disclosure of personal information that is to be conveyed to a government agency and which would put them in breach of the CAB's Code of Ethics. It places them in an untenable and unfair situation." (Written submitter - used with permission)

> "Disclosure of private, identifiable details would breach the privacy and confidentiality of clients under the professional ethics of all professions in our service (Counsellors, Psychologists and Social Workers)." (Survey respondent)

⁴⁷ <u>http://www.swrb.govt.nz/complaints/code-of-conduct</u> (accessed on 31 March 2017 - see Appendix C). ⁴⁸ <u>http://www.hdc.org.nz/the-act--code/the-code-of-rights</u> (accessed on 31 March 2017 - see Appendix C). 49

http://www.nzac.org.nz/code_of_ethics.cfm (accessed on 31 March 2017 - see Appendix C).

⁵⁰ http://www.psychologistsboard.org.nz/cms_show_download.php?id=237 (accessed on 31 March 2017 - see Appendix C).

http://www.legislation.govt.nz/act/public/2002/0039/46.0/DLM157813.html (accessed on 31 March 2017 - see Appendix C).

8.0 Security of personal information

8.1 Privacy principle 5 requires agencies holding personal information to take reasonable steps to protect the information against unauthorised access, use, modification and disclosure, as well as any other misuse. This obligation is particularly important where NGOs are being asked to assure their clients on MSD's behalf that ICLD will be kept safe.

"Our further concern is that people do not trust the security of MSD data storage, there have been: privacy breaches where an individuals' information is given to the media, computer security breaches, files being sent to old addresses, lost documents in the multitude; so this lack of trust is not without basis." (Written submitter)

- 8.2 MSD has reported to Ministers⁵² that it has a "three-pronged approach to developing the Information Technology (IT) systems to support data collection, transfer and storage". Phase one of data collection will be serviced by a "basic immediate solution (spreadsheet)". The second prong is that MSD will develop and manage an IT platform in conjunction with an IT partner. The third prong will involve MSD engagement with third party vendors of client management systems, and with large providers with their own client management systems.
- 8.3 MSD has reported that the spreadsheet and instructions for using it have been sent to programmes and services that will be required to collect ICLD. An NGO representative shared a printout of the spreadsheet and fact sheet on how to use it.
- 8.4 Spreadsheets lack in-built security protections, have been associated with significant data breaches, and are not likely to foster NGO or public trust. A spreadsheet does not appear to be a suitable repository for potentially very sensitive information about traumatic life events (e. g. that domestic violence counselling services have been provided to an individual).
- 8.5 MSD has advised NGOs that they need to "submit the data using a secure platform (the Shared Workspace) by 10 April 2017" and MSD will "send you information by the end of November [2016] about how to register for and use the Shared Workspace." MSD advised my staff on 29 March 2017 that this platform is owned and operated by the Department of Internal Affairs and that each NGO will nominate specific users for uploading ICLD into the shared workspace.
- 8.6 In the same⁵³ report, MSD told Ministers that its IT team had completed procurement of an IT system that is able to collect ICLD over the long term. MSD is carrying out proof of concept and testing work on this system with three providers. However the system is not due for completion until 1 July 2018.
- 8.7 It is unclear whether MSD will be able to use the ICLD it collects for assessing the effectiveness of services between now and 1 July 2018 when its IT system is completed.

⁵² Report to Hon Jo Goodhew, Associate Minister for Social Development and Hon Anne Tolley Minister for Social Development, Status update on Community Investment's collection of Individual Client Level Data and Information Communications Technology solutions, 1 December 2016.
⁵³ ibid.

8.8 I am concerned that IT system that underpins the collection and use of ICLD is underdeveloped and potentially vulnerable to data breach. An underdeveloped IT infrastructure increases the risk of loss, access, unauthorised disclosure and misuse of the stored information. In addition, the absence of a robust MSD IT infrastructure for storing and analysing the data calls into question the utility of collecting ICLD at this point in time.

> "We have always collected personal information for our own records BUT this information is held under the rules of the Privacy Act and is destroyed at its end, nor do we divulge the information we collect to third parties without the client's express (written) consent." (Survey respondent)

- 8.9 Separately,⁵⁴ MSD has reported that "all the data that we collect will be transferred into our MSD data warehouse, this will enable us to then match it with other data sets we hold on the clients. We will then be able to analyse the data across a wide range of fields, including their ethnicity, history of benefit uptake and programmes and services received." We understand that MSD's data warehouse is an existing tool that has been in place for some time and is primarily used for data matching.
- 8.10 The data warehouse is not a new or unique tool for analysing NGO service provider effectiveness or the appropriateness of specific services to individual clients or cohorts of clients. Access to the data warehouse is restricted to authorised users only. We understand that MSD also intends to share ICLD with Statistics New Zealand's Integrated Data Infrastructure (see paragraph 9.7 below) once it has undertaken its own analysis and matching work.
- 8.11 Updated guidance on MSD's website⁵⁵ states that ICLD will only be seen by its data and reporting analysts and that contract or relationship managers will not have access to ICLD. The same webpage says "[a]Il our staff are subject to the MSD Code of Conduct, which prohibits the misuse of data."
- 8.12 In communications with NGOs and my staff, MSD has relied on its Code of Conduct as evidence that the information collected under the ICLD will be secure. MSD's website refers to the Code of Conduct launched in 2011 saying "the Code of Conduct provides staff with guidelines and expectations about conduct that will not be tolerated, and the consequences of not meeting those expectations. Because of our role, we have a zero-tolerance approach to the misuse of personal information. This includes the deliberate and unauthorised release of sensitive information to third parties and for pecuniary gain. The consequences for staff include dismissal and referral to the Police. In addition to any penalty the Court may impose, if any money has been fraudulently obtained, it must be repaid in full."⁵⁶
- 8.13 MSD reports to Ministers and public documents indicate that MSD is aware of the potential privacy and security issues that the ICLD policy raises. The Community

⁵⁴ Memo to Kate Satterthwaite Private Secretary Office of Hon Jo Goodhew Associate Minister for Social Development from Maree Roberts, Associate Deputy Chief Executive, Community Investment *Response to Non-Government Organisations (NGOs) concerns about Individual Client Level Data (ICLD) Collection* 7 December 2016.

⁵⁵ <u>https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/community-investment-strategy/individual-client-level-datacollection.html (accessed on 31 March 2017).</u> ⁵⁶ <u>https://www.msd.govt.nz/about-msd-and-our-work/publications_recourses/community-investment-strategy/individual-client-level-data-⁵⁶ <u>https://www.msd.govt.nz/about-msd-and-our-work/publications_recourses/community-investment-strategy/individual-client-level-data-⁵⁶ <u>https://www.msd.govt.nz/about-msd-and-our-work/publications_recourses/community-investment-strategy/individual-client-level-data-⁵⁶ <u>https://www.msd.govt.nz/about-msd-and-our-work/publications_recourses/community-investment-strategy/individual-client-level-datastrategy/individual-client-level-datapublications_recourses/community-investment-strategy/individual-client-level-datastrategy/individual-client-level-datapublications_recourses/community-investment-strategy/individual-client-level-datastrategy/individual-client-lev</u></u></u></u>

⁵⁶ <u>https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/corporate/annual-report/2012-2013/maintaining-performance-integrity.html</u> (accessed on 31 March 2017).

Investment Strategy update 2016 states "We are very aware of the importance to keep client level data secure. A Security Risk Assessment will be undertaken by 31 October 2016 to ensure the data collection mechanism we use is appropriate and secure."⁵⁷

- 8.14 In an aide-mémoire dated 29 September 2016 MSD advised Associate Minister Goodhew that it was "working on a Privacy Impact Assessment (PIA) to identify any potential privacy risks and mitigations." MSD has yet to complete either a security risk assessment or a PIA.
- 8.15 In my view the lack of implemented security controls and policies represents an unacceptable level of risk. The information that NGOs are being required to share, while not extensive, may be extraordinarily sensitive for instance, that a woman has accessed Women's Refuge. I am not convinced that MSD has taken sufficient steps to consider and mitigate the security risks of collecting such high volumes of sensitive, identifiable information. Nor has MSD offered sufficient assurance of the protections for personal information collected under the ICLD policy.

8.16 **Complaints against MSD**

- 8.16.1 Complaints against MSD are a significant part of OPC's disputes resolution workload. Since 2008, 6 – 7% of complaint files closed each year were against MSD. Almost 60% of these involved people wanting access to information about them held by MSD, and 15% were about personal information being inappropriately used or disclosed by MSD. Of complaints currently being investigated at the time of writing, 9% involve MSD.
- 8.16.2 MSD is a data-rich organisation it handles large volumes of personal data within any given year. While most of this information is handled appropriately, there are times when errors occur and these affect public trust. Where errors have been made in the past, the public has a long memory for adverse consequences for individuals.

⁵⁷ Ministry of Social Development Investing in Services for Outcomes – Community Investment Strategy Update August 2016, p15.

9.0 How could MSD have done better?

- 9.1 The ICLD policy marks a significant shift in the way social services are delivered, and it is important to get it right. Features of the policy are likely to be replicated across a range of programmes in order to achieve the Government's social investment strategy. High volumes of sensitive personal information are involved. For a policy of this size and significance I would have expected MSD to take a precautionary approach, clearly identifying its purposes, considering the full range of options to achieve those purposes, assessing the relative merits and risks involved in each option and implementing the option with the least risks.
- 9.2 As this report has detailed above, MSD has not clearly articulated its objectives for collecting ICLD and the full range of purposes the personal information will be put to. Nor has it explained how the data it receives through this policy will achieve its aims of assessing the effectiveness of services. This failure has negatively impacted on the trust and confidence of NGOs and the people who will be affected by the policy. It has also meant that MSD missed an important opportunity to consider a range of options that would achieve its purposes, taking into account the volume and sensitivity of the data concerned.
- 9.3 Had MSD engaged early on, in an ongoing way with affected communities to ensure that its chosen approach would not negatively affect the individuals it was seeking to help, it may have achieved greater buy-in and support from NGOs and individuals from the outset.
- 9.4 I would also have expected MSD to identify and mitigate risks early on including by undertaking a thorough privacy impact assessment *prior* to implementing contractual changes and information collection processes. It is disappointing that a privacy impact assessment still has not been completed (as at 4 April 2017) and that privacy considerations were not prioritised much earlier in the process. The Privacy Act is an enabling statute that allows and facilitates a very wide range of information collection and disclosure practices. However information collection is always dependent on maintaining the trust of the people concerned. It is crucial that risks from information practices are identified and mitigated if provider trust is to be created and maintained. Less privacy invasive alternatives should have been considered.
- 9.5 My Office stands ready to assist agencies developing information sharing policies, MSD should have consulted with my Office regularly from the earliest stages of this policy being developed. It could also have considered a cross-government approach given the potential impact on other services and the potential for this policy to be replicated by other departments.
- 9.6 MSD could also have engaged with Statistics New Zealand to consider whether its policy objectives could be achieved entirely through Statistics New Zealand's Integrated Data Infrastructure.

9.7 The Integrated Data Infrastructure

- 9.7.1 If MSD's purpose for collecting this information is for research and analysis purposes, then using Statistics New Zealand's Integrated Data Infrastructure (IDI) may be a viable alternative to the current ICLD collection policy. Statistics New Zealand has a reputation for quality statistical analysis. It has years of experience and rigorous systems in place to collect, analyse and use large volumes of highly sensitive data. Unlike MSD, Statistics New Zealand does not have an operational focus, nor does it take adverse actions against individuals. MSD could still achieve its social investment goals using deidentified information by way of the secure cross-government IDI platform.
- 9.7.2 The IDI is supported by robust security and operating protocols. It operates under a "five safes" framework to ensure that the data is used appropriately with minimal risk to the privacy of the individuals to whom the data relates. The IDI de-identifies data, removing personal identifying information such as names and addresses, and encrypts identifiers such as IRD and NHI numbers. Approved researchers may only access data relating to their research. Research is restricted to the analysis of groups, not individuals, and must be in the public interest. NGOs I spoke with indicated they have high levels of trust in the IDI and would be comfortable with client data being put into the IDI for de-identified research and analysis.
- 9.7.3 In my view, MSD has not adequately considered how the IDI could be used as an alternative means to achieve MSD's policy objectives while minimising privacy risks.

10.0 Conclusion

"Many community workers will tell you that the people who most need their assistance are those least willing to engage; this issue of people failing to access the community assistance they need, will be greatly exacerbated should this policy be enacted". (Written submitter)

- 10.1 Implementing a significant new information gathering policy without sufficient evidentiary basis and without adequate consultation amounts to a serious deficit in the policy development process. Examining the ICLD policy process has shown gaps in the development and communication of MSD's goals.
- 10.2 My view is that MSD has executed the collection of ICLD prematurely without adequate consideration of the privacy risks involved and appropriate mitigation of those risks. Nor has it taken sufficient time to understand the full range of concerns of those affected.
- 10.3 This policy represents a new direction for the Government, and is likely to be the first of many occasions when agencies might seek greater access to personal information as a condition of receiving a service. As such, there is a need to proceed with caution and only implement the policy once robust security and information management processes are in place. It is essential that MSD learn from this policy, including the inadequate development process, the views of NGOs and the recommendations in this paper.
- 10.4 MSD has not clearly articulated with appropriate specificity what the ICLD is needed for, the full range of immediate uses and potential future uses under consideration (including matching with other agencies' data and profiling of individuals). More work needs to be done to define and communicate all the potential uses MSD is considering. In addition, the purpose needs to match the information collected. If the primary purpose of the policy is for analysing usage trends, this could be achieved with anonymous data.
- 10.5 Without a thorough privacy impact assessment, the success of MSD's policy is in jeopardy. Lack of public trust or a significant data breach will undermine the viability of this project long term. The reach of these consequences are not limited to MSD and could threaten individuals' overall trust of the Government in its use of personal information, and the credibility of its wider social investment agenda.
- 10.6 Allowing individuals to opt out of ICLD collection without affecting the funding for those individuals would meet MSD's legitimate need to assess service effectiveness but in ways that do not carry the risks of deterring vulnerable people from accessing the help they need. To that end, I welcome indications of MSD's willingness to consider the 12 month delay in implementing the ICLD policy for NGOs offering sexual violence services, and the consideration of a 10% client opt-out rate.
- 10.7 Requiring ICLD for all recipients of MSD-funded NGO support is not justified or proportionate and is therefore inconsistent with the principles of the Privacy Act and has the potential to infringe individual privacy.

Appendix A: Inquiry timeline

13 JANUARY 2017

Assistant Commissioner Joy Liddicoat wrote to MSD Chief Executive Brendan Boyle to inform him of the Privacy Commissioner's intention to conduct an inquiry into the collection of ICLD. Ms Liddicoat's letter outlined the purpose of the inquiry and the process we would follow.

31 JANUARY 2017

The Office of the Privacy Commissioner (OPC) distributed an online survey to NGO representatives affected by the ICLD policy seeking NGO views on the likely impact this policy would have on their service and clients. OPC received 548 responses to the survey which closed on 15 February 2017. A number of NGOs sent in written submissions. The respondent NGOs were diverse: ranging in size from supporting less than 100 clients, to those supporting more than 5,000 clients. Services offered include addiction support, aged care, budgeting advice, children and whānau services, health, housing, parenting, sexual trauma, Māori, Pasifika, violence, health, disabilities and youth services.

9 FEBRUARY 2017

MSD provided OPC with a package of 17 documents outlining advice given and received on the ICLD policy.

WEEK BEGINNING 13 FEBRUARY 2017

The Privacy Commissioner met with a number of NGO representatives to discuss their concerns about the ICLD policy including privacy and confidentiality issues.

OPC staff analysed the survey responses and written submissions, spoke with a number of NGO representatives either in person or by telephone and analysed the information provided by MSD in light of agencies' obligations under the information privacy principles in the Privacy Act 1993.

9 MARCH 2017

A draft version of the report was sent to MSD for its consideration and views.

27 MARCH 2017

MSD's response received.

Appendix B: Relevant Legislation

CHILDREN YOUNG PERSONS AND THEIR FAMILIES ACT 1989

s403 Approval of community services

- (1) The chief executive may, from time to time, on application by any person, body, or organisation whether incorporated or unincorporated, approve any service as a community service for the purposes of this Act, either generally or subject to such limitations as the chief executive may specify.
- (2) The chief executive may grant an approval under this section subject to such conditions as the chief executive thinks fit.
- (3) The chief executive shall not approve any service to be a community service unless the chief executive is satisfied that the service will provide services designed to further all or any of the objects of this Act (as set out in section 4).

s406 Financial assistance to community services

- (1) Subject to any general directions given from time to time by the Minister, the chief executive may, from time to time, make grants or provide financial assistance to any community service.
- (2) Any grants made, or financial assistance provided, under subsection (1) may be made or provided on such conditions, including conditions as to repayment and the giving of security to secure repayment, as the chief executive thinks fit.

s407 Chief executive may contract with community services for provision of services

The chief executive may from time to time, on behalf of the Crown, enter into a contract with any community service for the provision, by that community service, of such services as the chief executive considers necessary or desirable for the purposes of enabling the chief executive to carry out any function imposed on the chief executive by or under this Act.

CHILDREN YOUNG PERSONS AND THEIR FAMILIES ACT 1989

s4 Objects

The object of this Act is to promote the well-being of children, young persons, and their families and family groups by:

- (a) establishing and promoting, and assisting in the establishment and promotion, of services and facilities within the community that will advance the well-being of children, young persons, and their families and family groups and that are:
 - (i) appropriate having regard to the needs, values, and beliefs of particular cultural and ethnic groups; and
 - (ii) accessible to and understood by children and young persons and their families and family groups; and
 - (iii) provided by persons and organisations sensitive to the cultural perspectives and aspirations of different racial groups in the community:
- (b) assisting parents, families, whānau, hapu, iwi, and family groups to discharge their responsibilities to prevent their children and young persons suffering harm, ill-treatment, abuse, neglect, or deprivation:

- (c) assisting children and young persons and their parents, family, whānau, hapu, iwi, and family group where the relationship between a child or young person and his or her parents, family, whānau, hapu, iwi, or family group is disrupted:
- (d) assisting children and young persons in order to prevent them from suffering harm, illtreatment, abuse, neglect, and deprivation:
- (e) providing for the protection of children and young persons from harm, ill-treatment, abuse, neglect, and deprivation:
- (f) ensuring that where children or young persons commit offences,-
 - (i) they are held accountable, and encouraged to accept responsibility, for their behaviour; and
 - (ii) they are dealt with in a way that acknowledges their needs and that will give them the opportunity to develop in responsible, beneficial, and socially acceptable ways:
- (g) encouraging and promoting co-operation between organisations engaged in providing services for the benefit of children and young persons and their families and family groups.

SOCIAL SECURITY ACT 1964

s60 GAG Obligations to work with contracted service providers

- (1) A person who is receiving in his or her own right, or as the spouse or partner of the person granted the benefit concerned, an emergency benefit, sole parent support, supported living payment, or jobseeker support, is subject to the following obligations:
 - (a) when required by the chief executive, to attend and participate in any interview with a contracted service provider specified by the chief executive:
 - (b) when required by the chief executive, to attend and participate in any assessment of the person undertaken on behalf of the chief executive by a contracted service provider specified by the chief executive:
 - (c) when required by the chief executive, to co-operate with a contracted service provider specified by the chief executive in facilitating the provision of the services that the provider has been contracted to provide in relation to the person's obligations under all or any of the following:
 - (i) section 60Q (work preparation obligations):
 - (ii) section 60RA(3) (social obligations):
 - (iii) conditions (subject to which an emergency benefit is granted or continued) that the chief executive thinks fit to impose, or determines, under section 61(1) or (3):
 - (iv) section 102A (work test obligations):
 - (d) when required by the chief executive, to report to a contracted service provider specified by the chief executive on the person's compliance with the person's obligations under this Act as often as, and in the manner that, the provider reasonably requires.
- (2) The chief executive must take reasonable and appropriate steps to make every person on whom obligations are imposed under subsection (1) aware of—
 - (a) those obligations; and
 - (b) the consequences of failure to comply with those obligations.
- (3) A person who fails without a good and sufficient reason to comply with an obligation imposed on the person under subsection (1) is subject to the sanctions under section 117.

VICTIMS RIGHT ACT 2002

Privacy of victims

15 Victim's rights under Privacy Act 1993

- (1) No person may interfere with the privacy of a victim contrary to the Privacy Act 1993.
- (2) This section is not limited by section 7, and does not limit or affect, or give any person any rights separate from, or additional to, the Privacy Act 1993.

16 Restriction on disclosing victim's contact details in evidence or information provided to court

- (1) This section applies to information (the **information**) that discloses, or that may lead to the disclosure of, a victim's contact details.
- (2) The information may be given in evidence or in information provided to a court only with the leave of the judicial officer.
- (3) The judicial officer must not grant leave unless satisfied—
 - (a) that the information is directly relevant to the facts in issue in the proceedings; and
 - (b) that the evidential value of the information (if any) outweighs any prejudice to the victim's interests, or any harm to the victim, that is likely to be caused by the giving of the information.
- (4) In this section, **contact details** means any 1 or more of the following:
 - (a) residential address:
 - (b) postal address:
 - (c) email address:
 - (d) home telephone number:
 - (e) business telephone number:
 - (f) mobile telephone number:
 - (g) fax number

16A Criminal proceedings to which section 16 does not apply

Nothing in section 16 applies to a criminal proceeding if it is necessary to disclose the information in the charge in order to ensure that the defendant is fully and fairly informed of the nature of the charge.

Appendix C: Extracts from Professional Codes of Ethics

SOCIAL WORKERS REGISTRATION BOARD CODE OF CONDUCT

Principle 7 Respect the client's privacy and confidentiality

You are expected to:

- 7.1 protect the privacy of the client's personal information
- 7.2 treat information gained in the course of the social worker/client relationship as confidential information and use it for professional purposes only
- 7.3 inform clients of the extent to which any other professionals or employees will be able to access client records
- 7.4 inform clients of the extent of confidentiality and the situations where the information may need to be disclosed and wherever possible advise your client of such a situation
- 7.5 store records securely and make sure these are only accessed or removed for social work or professional purposes
- 7.6 use technology with diligence and care to protect client privacy and take special precautions to protect client information in any electronic records, emails, documents, notes, or any other place where client information is held
- 7.7 maintain client confidentiality and privacy by not referring to any client or client-practice issue in public places including in social media⁵⁸ as even if identifying data such as names or place of residence are not included or referred to, the client may still be recognisable.

Respect the client's privacy and confidentiality – Guide

Confidentiality and privacy are related but distinct concepts.

Confidential information is about the data gathered about clients. Clients have an expectation that such information will only be disclosed in certain circumstances. Sharing information within the social work or interdisciplinary teams is, at times, essential for best client management or where a child's or other people's safety is at risk. However, if that confidential information is disclosed without authorisation or justification, then we say that the person's privacy has been breached.

Privacy is more related to the person. People are entitled to a private life and to keep personal information to themselves. Privacy is related to the client's expectation to be treated with dignity and respect. The social worker/client relationship is built on trust and clients will be reluctant to disclose their most personal information if they fear it will be disseminated beyond those who have a legitimate need to know. Any breach of this trust, even inadvertent, damages the particular social worker/client relationship and general trustworthiness of the social work profession.

You need to be aware of the laws, codes, regulations, and policies that relate to privacy and confidentiality. They are found in places such as (but not limited to):

- the Privacy Act 1993
- the Health and Disability Commissioner's Code of Health and Disability Services Consumer Rights Regulations 1996
- the Health Information Privacy Code 1994
- employers' policies or guidelines.

⁵⁸ This applies to social-networking sites (for example, LinkedIn, Facebook, MySpace, blogs, emails, Twitter) and other electronic media.

These outline when you can disclose information about a client. You may be able to disclose information about a client, for example, to prevent or lessen a serious and imminent threat to public health, public safety, or to the life or health of a client or another person (see Health Information Privacy Code, Rule 11).

The decision not to advise a client of the disclosure of information requires careful consideration. This is likely to occur only in very exceptional circumstances, such as when notifying them about the disclosure would expose others to risk (for example, in some child-protection matters) or where there is a specific requirement that prohibits such a disclosure.

Consult with senior colleagues and other appropriate professionals (including seeking legal advice) before disclosing information without your client's consent.

See the websites of the Health and Disability Commissioner and the Office of the Privacy Commissioner for more detailed information.

CODE OF ETHICS FOR PSYCHOLOGISTS WORKING IN AOTEAROA NEW ZEALAND

1. 6. Privacy and Confidentiality:

Value Statement:

Psychologists recognise and promote persons' and peoples' rights to privacy. They also recognise that there is a duty to disclose to appropriate people real threats to the safety of individuals and the public.

Practice Implications:

- 1.6.1. Psychologists make themselves aware of relevant Acts and Standards and follow procedures that provide for informed consent, confidentiality, fair treatment and due process as laid out in those Acts and Standards.
- 1.6.2. Psychologists explain clearly the measures they will take to protect confidentiality when engaged in services to, or research with, individuals, families, groups, or organisations. Furthermore, psychologists convey to family, hapū/iwi organisations, and community members the responsibilities on them for the protection of each other's confidentiality.

Comment: Psychologists should take care to protect confidentiality of participants in groups with which they work by emphasising participants' obligation to one another (eg. in group therapy or research focus groups).

- 1.6.3. Psychologists discuss with persons and organisations with whom they establish a research or professional relationship (a) the limits of confidentiality as defined in 1. 6. 10 and (b) the foreseeable uses of the information generated through their services/activities.
- 1.6.4. Psychologists seek to collect only that information which is germane to the purpose(s) for which informed consent has been obtained.
- 1.6.5. Psychologists record only that information necessary for the provision of continuous, coordinated service to a client, or for validating or identifying conclusions in a report, or for the goals of the particular research study being conducted, or which is required by law.
- 1.6.6. Psychologists store, handle, transfer and dispose of all records, both written and unwritten *(eg, computer files, video tapes)*, in a way that attends to needs for privacy and security.
- 1.6.7. Psychologists retain information as defined in current legislation or ethical guidelines (for research data).

Comment:

- (a) Information includes paper records and computer records.
- (b) Records should be accessible and legible.
- (c) Adequate plans should be made for access to and disposal of records for circumstances of one's serious illness or death.

- 1.6.8. Psychologists take all reasonable steps to ensure that information over which they have control remain retrievable as long as is necessary to serve the interests of those to whom they refer and/or the purpose for which they are collected, or as required by law.
- 1.6.9. Psychologists do not disclose personal information obtained from an individual, family, whānau or community group or colleague without the informed consent of those who provided the information, except in circumstances provided for in 1. 6. 10.

Comment: Information to be protected includes any information gained second hand (e.g, from a colleague about their client or student) in activities as a psychologist, and where it could be anticipated that the information would be regarded by the person/s it concerns to be confidential.

1.6.10: Psychologists recognise that there are certain exceptions and/or limitations to nondisclosure of personal information, and particular circumstances where there is a duty to disclose. These are:

(a) Diminished capacity: Where a person is judged incapable of giving consent to disclosure themselves.

Comment: In such circumstances consent to disclose is sought from those who are legally authorised to represent their interests (*eg. parents of children/young persons, legal guardians of mentally incapacitated persons).*

(b) Children/young persons: The level of a child's/young person's emotional maturity and cognitive skills should determine the weight given to their requests and consent to disclose personal information.

Comment: Psychologists should recognise that significant health, safety, and/or relationship issues may override confidentiality and the wishes of the child/young person. In the situation that a psychologist intends to convey information to a third party, the child/young person should be informed if possible, and the matter should be discussed to a level that is age appropriate. Account should be taken of the child's/young person's limited capacity for individual responsibility, and the special status of children/young persons in relation to their guardians.

(c) Urgent need: Where a situation arises when it is impossible or impracticable to seek consent to disclosure in time to prevent harm or injury to the person, persons, family, whānau, or community group.

Comment: In these circumstances psychologists should report to the person, persons, or the person authorised to represent his/her interests, as soon as practicable, any information disclosed to a third party.

(d) Legal requirements: Where a psychologist is compelled by law to disclose information given by a client or research participant.

Comment: For example, mandated assessments and treatments, court order to disclose information from files or other records. In such circumstances psychologists inform the person or persons in advance, where possible, of such limitations to confidentiality that may exist.

(e) Client or public safety: Where a psychologist believes that non-disclosure may endanger a client, research participant or another person but is denied permission to disclose, the psychologist exercises professional judgement in deciding whether to breach confidentiality or not.

Comment: Psychologists should consult with senior colleagues before making their decision. Ultimately, they must be able to justify the decision made.

1.6.11. Psychologists, in disclosing information as allowed for in 1. 6. 10, provide only that information which, in their opinion, is accurate and relevant to the situation.

Comment: Psychologists should ensure that any limitations of the information provided are made clear to the recipient.

1.6.12. Psychologists ensure that where client and/or research information about individuals or groups is used in publications, teaching or public presentations, the identity of the clients or research participants concerned is protected.

Comment: Unless informed consent has been obtained for identification and presentation.

1.7. Informed Consent:

Value Statement:

Psychologists recognise that obtaining informed consent from those with whom they are working is a fundamental expression of respect for the dignity of persons and peoples.

Practice Implications:

1.7.1. Psychologists accept the obligation to obtain or negotiate informed consent in a manner consistent with the principles of this Code.

Comment: Some individuals or groups have less power than others, permanently or temporarily, placing them in a vulnerable position and increasing the responsibility of psychologists to protect and promote their rights. In exercising this responsibility psychologists seek to collaborate with the persons involved in devising and implementing appropriate safeguards.

- 1.7.2. Psychologists obtain explicit informed consent for any psychological services provided or for participation in research.
- 1.7.3. When working with a person or persons who are unable to give explicit consent for reasons of diminished capacity, age and/or intellectual and/or emotional immaturity, psychologists must gain the consent of the person's guardian(s). They should also seek informed consent to the extent feasible from the person with limited ability to consent, and taking into account the facts of their particular case.

Comment: It is the responsibility of the psychologist to obtain consent from an appropriate person/agency. A lawful basis for consent is required.

1.7.4. Psychologists ensure that informed consent is the result of an agreement to work collaboratively and they take all reasonable steps to ensure that consent is not given under conditions of coercion or undue pressure from them.

Comment: It is recognised that in certain work settings, psychologists are required to conduct assessments where consent may not be readily forthcoming *(e. g. , child protection work, forensic work)*.

- 1.7.5. When working with a person or persons from whom explicit informed consent cannot be obtained, psychologists proceed in accord with current statutory provisions.
- 1.7.6. In obtaining informed consent, psychologists provide as much information as a reasonable or prudent person, family, whānau, or community would want to know before making a decision or consenting to an activity.

Comment: This includes warning of any potential risks or consequences.

1.7.7. In obtaining informed consent, psychologists relay information in language that is easily understood, and give sufficient time for the recipients to respond to the information. Psychologists take whatever reasonable steps are necessary to ensure that the information was, in fact, understood.

Comment: Including providing translation into another language, if necessary.

- 1.7.8. In seeking informed consent for participation in research, psychologists ensure that the procedures and information provided meet the standards of a relevant human subjects ethics committee.
- 1.7.9. Psychologists accept that there may be some exceptions and/or limitations to a person or persons giving explicit informed consent. The major exceptions/limitations are:(a) Diminished capacity: Where a person is judged incapable of giving explicit informed

(a) Diminished capacity: Where a person is judged incapable of giving explicit informed consent themselves.

Comment: In such circumstances informed consent procedures are carried out with those who are legally authorised to represent their interests (*eg, parents of children, legal guardians of mentally incapacitated persons*).

(b) Urgent need: Where a situation arises when it is impossible or impracticable to obtain informed consent in time to prevent harm or injury to the person, persons, family, whānau, community group or some other person.

(c) Legal requirement: Where a psychologist's actions are mandated by law.

Comment: As in some treatments or assessments contracted by the Courts *(eg, those carried out under criminal, mental health or family law)*. Psychologists inform the client of these limits at the commencement of their work.

HEALTH AND DISABILITY COMMISSIONER CODE OF HEALTH AND DISABILITY SERVICES CONSUMERS' RIGHTS REGULATION 1996

Right to be Treated with Respect

- 1) Every consumer has the right to be treated with respect.
- 2) Every consumer has the right to have his or her privacy respected.
- 3) Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori.

NEW ZEALAND ASSOCIATION OF COUNSELLORS CODE OF ETHICS

6. CONFIDENTIALITY

6.1 Extent of Confidentiality

- a. Counsellors shall treat all communication between counsellor and client as confidential and privileged information, unless the client gives consent to particular information being disclosed.
- b. Counsellors may discuss, in supervision, information received in counselling as part of the normal management of confidentiality.
- c. Counsellors should take all reasonable steps to communicate clearly the extent and limits of the confidentiality they offer clients. Any agreement between the counsellor and client about confidentiality may be reviewed and changed by joint negotiation.
- d. Counsellors shall protect clients' identities when information gained from counselling relationships is used for purposes such as counsellor training, research or audit.
- e. Counsellors shall respect confidences about the clients of colleagues.
- f. Counsellors should establish procedures to ensure the ongoing management of client confidentiality in the event of the counsellor's death.

6.2 Exceptions to Confidentiality:

- a. Counsellors shall only make exceptions to confidentiality in order to reduce risk.
- b. When counsellors need to pass on confidential information, they should provide only the minimum of information necessary and only then to those people to whom it is absolutely necessary.
- c. Exceptions to confidentiality occur when:
 - there is serious danger in the immediate or foreseeable future to the client or others,
 - the client's competence to make a decision is impaired,
 - legal requirements demand that confidential material be revealed,

- responding to a complaint about counselling practice.
- d. Wherever possible, the decision to make an exception to confidentiality is made:
 - after seeking the client's co-operation, unless doing so would further compromise the safety of the client or others,
 - after consultation with a supervisor.

6.3 Confidentiality and the law

- a. Counsellors are encouraged to seek legal advice about their rights and obligations under the law, when the counsellor's work with clients involves contact with the legal system.
- b. When issued with a search warrant or subpoena to give evidence in Court, or other legal processes, counsellors should pursue the status of privileged communication, in accordance with the client's wishes, until all legal avenues have been exhausted.