

Government Data & Privacy Issues for Community Social Services

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What MSD originally proposed

Where things are at now

The Big Data landscape

The issues associated with government
collection of data on individuals

The issue . . .

Individual Client Level Data – ICLD

Or in other words . . .

No Data, No Funding

NGOs to hand over people's personal information in return for government funding. A contract requirement.

What information will you will share with MSD?

The following information will be shared:

Client demographic information	Name, date of birth, address, gender, ethnicity, iwi and country of birth
Dependents	Number of dependents Date of birth of youngest dependant
Service detail	Programme/service name, start date and end date, source of referral

MSD is not interested in your case notes, or your personal files.

Affects . . .

Ordinary citizens

Anyone seeking advice from an agency that gets some funding from MSD

Helping agencies

NGOs that get some funding from MSD for services to individuals

WHY WERE WE
WORRIED?

Will gathering administrative data on individuals improve services?

The connection is not apparent.

Governments and service providers need information.
But we cannot ignore issues of . . .

- Privacy
- Purpose
- Risk
- Ethics

Concerns for citizens

As a citizen who seeks help—

- You will go on a database of “vulnerable people”
- Your children will be in the database
- You will be subject to risk profiling
- You don’t know how long the data will be held
- Or what it will be used for
- Or who will see it

And we know MSD data isn’t always totally secure.

Concerns for providers

Service impacts:

- Our services are built on the promise of confidentiality
- People who need help may not seek it
- Professional ethics

Funding impacts:

- No agreement to provide data, no contract
- Funding cuts if service users refuse to go on database
- Hefty compliance costs

Appendix One: Advantages and disadvantages to mandatory sharing versus opting out

	Mandatory	Sensitive services customers choosing to opt out
	Consent to share data is required to receive an MSD funded social service.	Customers opting out will still receive the MSD funded service. The phasing in of exempt services will start from July 2017, with all services included by December 2018.
Advantages	<p>Able to undertake complete cross analysis on social investment including collective impact across Government investment to better support customers and direct funding.</p> <p>Will better enable Government and Providers to track customer journeys where complex and longer term support is required.</p> <p>Support MSD to understand where and how to invest appropriately, based on effectiveness and efficiencies of services and/or Providers.</p> <p>Allows for a cohesive customer centred approach to services.</p> <p>Less likely to raise customer data and volumes.</p>	<p>Customers of sensitive services would have their data safeguarded to help protect their privacy and to facilitate their engagement with services.</p> <p>This mitigates the compulsory requirement to provide consent for sensitive services.</p>
Disadvantages	<p>Some customers are likely to have significant concerns, and/or refuse to provide information.</p> <p>There are concerns across the sector that the ability for a Government agency or Provider to decline service to a potential customer because they will not consent to sharing information potentially reflects the tensions between informed consent versus coercive consent.</p>	<p>MSD will not be able to assess the efficiency, effectiveness and ROI of services and programmes where customers choose to opt out or providing consent.</p> <p>Customers opting out may not receive the full benefit of seamless services if they are not able to be identified and appropriately supported by their Provider.</p>
Notes and caveats	<p>All customers and Providers are required to share customer data on the appropriate MSD funded services, otherwise service is declined. Some services (eg medical and counsellors etc) require this as part of their professional accreditation.</p> <p>Some services such as low contact services will not and do not capture customer names etc.</p> <p>Note that some services already collect customer data, and some statutory services require consent and data sharing otherwise services cannot be provided.</p>	<p>CI needs to do further work to identify what services would be phased in and when, and what services will be exempt and provide anonymised data.</p>

Coercion

“The ability . . . to decline service to a potential customer because they will not consent to sharing information potentially reflects the tensions between informed consent and coercive consent.”

MSD report to Assoc Min Jo Goodhew March 2016

What social service providers say:

“The most hard to reach children and families will not reach out for help.”

“For me, privacy and confidentiality are the basis of the work I do with people in distress.”

“Whether family support, budgeting, counselling . . . the information is sensitive and private . . . Providing identifiable data to government agencies is risky. ”

Privacy Commissioner's Report

April 2017 report highly critical of MSD

“Excessive and disproportionate”

4 recommendations

- Consider alternative means to get information
- Ensure people not deterred from help seeking
- Need specific, relevant and clear reasons to collect data
- Robust security procedures needed

Government has had a very welcome change of mind

MSD is not proceeding with data collection from July 2017 – on hold

Responsibility to develop system for social sector data will be with Social Investment Agency, with Minister Amy Adams in lead role

Will be working with NGOs, Privacy Commissioner, Statistics NZ and others

We still have big challenges

Same issues need to be worked through: reason for data collection, privacy, ethics, security protocols, compliance costs

System is intended for “wider social sector” – includes health?

Community mandate for big data

Government's social investment agenda

Impact for NGOs

The Data Landscape

(it's looking abit crowded!)

Data Futures Partnership

- Social Licence
- Data Commons
- Re-identification

What does good data use look like for NZ?

an alternative common's owned approach to creating data sharing platforms with high trust & control of participants

Stats NZ

IDI

Integrated Data Infrastructure

- wants to be Repository of all govt/NGO Data
- strict access criteria for researchers to anonymised data sets
- current capacity issues slowing expansion

IDIA

'Shared workspace' Shared Data system across agencies for service delivery

as opposed to a govt driven approach to sharing data about clients by agencies (altho some obsurmo - of controlled access)

SIU

Social Investment Unit

- Data Exchange - tools to enable transfer of data between agencies, NGOs
- Analytics of IDI data
- Using Actuarial model for risk factors
- Some overview/oversight of what SI is in NZ & how applied by govt agencies

these may link - infrastructure

Supery

- Evaluation/Research function
- What is evidence telling us

Treasury

- Analytics of IDI data
- Inform budget plans
- Actuarial model to identify forward liability & risk factors (now sitting in SIU)

iMSD

- SI applied to welfare reforms

CI (MSD)

- Community Investment
- ICHD approach
- Funding 'what works' intent

NGO's

- Increasing use of CMS tools & using data analytic tools (eg PowerBI / Tableau)
- More data-driven with intro of RBA, Intervention logics, Theory of change etc
- Investment needed to increase capability
- Some NGO's loading data into IDI

NGO's having to navigate across the whole landscape

Everyone wants 'our' data but who's data is it - our clients!

Big Data - multiple initiatives underwa

- Social Investment Unit – building a data exchange system (www.siu.govt.nz)
- Statistics NZ - IDI Integrated Data Infrastructure – “de-identified” microdata about people and households (stats.govt.nz/idi-data)
- Data Futures – leading discussion with citizens about data – “social licence” (www.datafutures.co.nz)
- Data Commons – “A high-trust, lower-cost alternative to enable data integration and reuse” (datacommons.org.nz)
- DIA – government lead on IT and information
- Work of Superu, Treasury, and NGO sector

Where does the citizen fit in all this? How is our mandate obtained?

Social investment

Some positives: It makes sense to spend early to avert later (and more serious) problems. Enabling cross-sector spending makes sense.

But there are concerning aspects:

- Use of predictive risk modelling
- Ethical and privacy considerations
- Potential to be used for targeting and rationing of services

What does all of this mean for the community sector?

We're concerned about community organisations becoming or being seen as an arm of the state

The relationship between government and the community sector is an uneasy one, for both parties. The term “providers” is market language – the sector has in part bought into that paradigm.

The ‘market-building’ approach of government is challenging a community-led development model