



28 September 2018

S18.37

## Submission to the Social Investment Agency on Your Voice, Your Data, Your Say

### Introduction

- 0.1. The National Council of Women of New Zealand, Te Kaunihera Wahine o Aotearoa (NCWNZ) is an umbrella group representing over 200 organisations affiliated at either national level or to one of our 15 branches. In addition, about 450 people are individual members. Collectively our reach is over 450,000 with many of our membership organisations representing all genders. NCWNZ's vision is a gender equal New Zealand and research shows we will be better off socially and economically if we are gender equal. Through research, discussion and action, NCWNZ in partnership with others, seeks to realise its vision of gender equality because it is a basic human right.
- 0.2. This submission has been prepared by the NCWNZ Public Issues Standing Committee and the Parliamentary Watch Committee after consultation with the membership of NCWNZ. It draws the responses of NCWNZ branches throughout Aotearoa New Zealand.
- 0.3. NCWNZ is making this submission to the SIA (Social Investment Agency) in response to a request for input by community organisations for input into the development of the government's approach to:
  1. **Investing for social wellbeing** – a way of working to support New Zealanders to live the lives to which they aspire
  2. **Data protection and use policy** – to provide clear guidance for how personal information can and can't be used in the social sector
- 0.4. A representative of the National Council of Women of New Zealand participated in a hui for non-governmental organisations in Christchurch on Wednesday 22 August 2018. Participation in the Christchurch hui for non-governmental organisations also informed this submission. Unlike many organisations responding to issues relating to investing for social wellbeing and data protection and use, NCWNZ is not a provider of social services, but includes representatives of organisations that are involved in social service provision, often on contract to the government. Members who contributed to this submission included those working in the social sector, including work on coordinating the sharing of information across agencies. There was also advice from social researchers with expertise in research ethics. The focus of the submission is primarily on the key principles that should inform

practices with respect to action directed at wellbeing and the recording, storage, use and sharing of personal information by non-governmental and state agencies.

## 1. Investing for social wellbeing

### Putting people at the centre

- 1.1. NCWNZ members supported the principle of putting people at the centre. However, one NCWNZ branch suggested that: “It is so easy to make broad, sweeping claims about being “people-centred” but to actually do this is very hard, especially if you are not clear about who exactly the people are and how you will respond to their potentially conflicting needs.”
- 1.2. One NCWNZ branch stated that people centredness would be best be achieved by having a system of case managers and recording of personal information that ensured that clients of support services did not have to tell their story over and over again to different people. They argued that government officials should operate on the assumption that most people seeking support are doing their best to manage their lives and should not experience intrusive pressure directed at proving their challenging life circumstances. An NCWNZ branch argued that: “Putting people first requires the ability to listen – and that takes time”.
- 1.3. Some NCWNZ members considered that putting people at the centre could involve focusing on the issues that are relevant to the individual client and their whānau rather than making assumptions about what they want and need. They also suggested that the creation of community hubs offering diverse services in a single location would make it much easier for people to access services and, in this way, make their needs central to service provision. NCWNZ members thought it was important that clients of services were given an opportunity to “take some ownership and embrace the changes that may be needed in order to create an improvement in their situation”.
- 1.4. The Tauranga Branch of NCWNZ indicated that a recent interagency autism project that operated through Support Net and involved the Ministries of Health, Education and Social Development had developed non-identifiable ways to record information about individuals and provide support across agencies. This allowed agencies to target identified individuals with wrap around support.

### Partnership between government and non-governmental organisations

- 1.5. NCWNZ considers that increased social wellbeing rests on more collaborative relationships between government agencies and non-governmental organisations that provide social services on contract to those in need. Social sector organisations are often closer to those accessing services than government agencies and have a greater sense of what is needed to make a difference. NCWNZ members considered there was a need for better two-way flows of communication between NGOs and government. State agencies and officials need to be more attentive to what social sector providers have to say about their clients and their needs. There cannot be successful investment for

social well-being until there is genuine partnership between those who directly provide services and government agencies that decided on funding for these services.

- 1.6. NCWNZ members considered that building trust with the clients of agencies, as well as trust between government and NGOs providing social services was very important. Clients take time to trust social service providers and trust between providers can be difficult when they are positioned as in competition with one another for government funding. One NCWNZ branch argued that trust between NGOs and trust between NGOs and government agencies could be enhanced if NGOs had longer contracts that would enable them to consolidate and improve their services and their relationships with clients. They stated that: “Fragmented funding amongst agencies when it is tagged can inhibit the achievement of goals and lead to suspicions of participants.”

#### **Provision of clear goals and robust measurement**

- 1.7. NCWNZ members raised questions about who defined these goals and what data was used to measure their achievement. A partnership model implies collaboration on goal setting. This collaboration should be among NGOs and government agencies, but also involve social sector clients engaged in personal goal setting and the achievement, with support, of these goals.

#### **Local and regional strategies for social wellbeing**

- 1.8. Those providing services at a local level often have a more detailed understanding of needs in their area than officials in government agencies. Increases in social wellbeing depend on attention to local needs and strategies and diversity among those accessing social services. A partnership approach to collaborative relationships between the social sector and state agencies could result in more effective interventions at local levels that contribute to the collective wellbeing of whānau, families and communities.

#### **The language of ‘investing for social wellbeing’**

- 1.9. There was some scepticism about the value of continuing to use ‘investment’ and business language when identifying strategies directed at achieving wellbeing. One NCWNZ branch considered that previously the SIA had tended to focus exclusively on an economic model for measuring wellbeing. Material wellbeing is very important; basic economic needs must be met for individuals, households and communities to thrive. But wellbeing is not simply material. Providing economic support in a ways that enhance human dignity and maximise the agency and self-determination of those receiving support is also important. One NCWNZ branch considered that changing the name of the SIA was not important as that could involve the use of money for branding that would be better spent on funding for services.

### Defining social wellbeing – issues and resources

- 1.10. NCWNZ members also considered that wellbeing was a rather vague concept. Concerns about the challenges of defining wellbeing and arriving at measures of wellbeing have been identified in recent NCWNZ submissions to other agencies.<sup>1</sup> Different dimensions of wellbeing needed to be identified and strategies directed at action relating to achieving change in the lives of individuals and their communities. Attention to wellbeing should include consideration of community wellbeing and not just individual wellbeing and also address cultural issues relating to wellbeing. Opportunities to preserve language, foster cultural festivals and children’s participation in the culture of their ancestors were all ways that enhance wellbeing and needed attention alongside warm, dry housing suitable for different sized families and resources to purchase healthy food and adequate clothing.
- 1.11. Māori understandings of what constitutes wellbeing need to be addressed in any attempt to develop strategies directed an ‘investment for wellbeing’. This will necessarily include attention to the relationships between people and the natural environment and between people and their ancestral land. In these respects, wellbeing cannot be confined to narrow consideration of what is provided by social sector agencies delivering services under contracts with state agencies. One NCWNZ branch suggested that understandings of wellbeing should include attention to the Te Whare Tapa Whā model which embraces all aspects of wellbeing – whānau (family health/wellbeing), tinana (physical health), hinengaro (mental health) and wairua (spiritual health).
- 1.12. NCWNZ considers that attention to what constitutes wellbeing should be informed by the following international and national efforts to identify key features of wellbeing:
- Convention on the Elimination of All Forms of Discrimination against Women [CEDAW] which identifies the following as key to women’s wellbeing: Participation in Public and Political Life, International Representation and Participation, Education, Employment, Health, Legal Rights, and Freedom from Domestic Violence.
  - Sustainable Development Goals – SDGs which include Zero Hunger, Health and Wellbeing, Quality education, Gender Equality, Clean water and sanitation, Affordable clean energy, Decent work and economic growth, Industry/Innovation/Infrastructure, and an overarching, ambitious vision of leaving no-one behind.
  - NCWNZ Gender Equal Work and Gender Dashboard themes: Economic Independence, Safety and Health, Equality in Education and the Workforce and Influence in Decision-Making.

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<sup>1</sup> S18.30 NCWNZ Submission to The Treasury on the Living Standards Framework. July 2018.  
<https://www.ncwnz.org.nz/wp-content/uploads/2018/07/S18.30-Living-Standards-Framework.pdf>

## 2. Data protection and use policy

### Consent to the recording, storage, use and sharing of personal information

- 2.1. NCWNZ has for some time been concerned about the need to protect the privacy of individuals and resolved in 1972 (before the Privacy Act 1993 was passed) that legislation was necessary to protect computerised personal files.<sup>2</sup> A remit passed in 1989 was critical of proposals to allocate to each person a single reference number that would be used by and be accessible to government departments and agencies. A recent NCWNZ submission supported the clarification in the Privacy Bill 34-1 2018 that agencies that record a unique identifier for a person that is used by another agency should not assign that unique identifier for use in its own operations.<sup>3</sup>
- 2.2. Previous NCWNZ submissions relating to privacy and protection of personal information have highlighted the need for effective and carefully administered informed consent processes if personal information is to be shared between agencies and between NGOs providing services and government, NCWNZ considers that those providing such information should be able to access and edit their personal data. It is also important that strategies are in place to ensure that the information shared is accurate.
- 2.3. One NCWNZ branch argued that the way data about individuals that is held on the Ministry of Health NASC (Needs Assessment and Service Coordination) server could be a model for other agencies. The Ministry of Health data base only has access to data that support their actions and each NASC throughout the country only has access to data relevant to that NASC's actions. Another NCWNZ branch stated that: "The principle should always be that at all times an individual should have access to information that is kept on them". They also considered that: "Personal information should never be gathered without the individual being told why and how the information will be used".
- 2.4. Current NCWNZ policy supports the protection of privacy in relation to electronic information and the upholding of Article 12 of the United Declaration of Human Rights which states that no-one should be subjected to arbitrary interference with respect to their privacy and that everyone has a right to protection of the law against such interference.<sup>4</sup>

### Factors inhibiting informed consent to the recording, use and sharing of information

- 2.5. NCWNZ members were concerned about the extent to which those accessing social services were in a position to choose to give informed consent to the recording, use of and sharing of personal information in a context in which they were seeking financial support or social services. It is possible

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<sup>2</sup> NCWNZ resolution 1972 – That Government is urged to legislate to protect the privacy of individuals in relation to computerized personal data files.

<sup>3</sup> S18.21 NCWNZ Submission to the Justice Committee on the Privacy Bill 34 – 1, 2018. <https://www.ncwnz.org.nz/wp-content/uploads/2018/05/S18.21-Privacy-Bill-34-1.pdf>

<sup>4</sup> S12.06 NCWNZ Submission to the Justice and Electoral Committee on the Privacy (Information Sharing) Bill 318-1, 2012. <https://www.ncwnz.org.nz/wp-content/uploads/2013/06/Privacy-info-sharing-Bill-S12-06.pdf>

that those who are asked to consent to the storage and use of their personal information may feel compelled to agree to this when they actually have concerns about the use of that information. One NCWNZ branch suggested that people asked to provide this personal information should have the option of a support person with them. They stated that: “People will want to know how sharing information will result in them getting better services, or better access to resources.”

### **Monitoring of the implementation of protocols**

- 2.6. NCWNZ members stated that it was critical that scrupulous and robust management of protocols is maintained in order that private and sensitive personal information is protected. Anyone providing information that will be used for research purposes should clearly consent to this, even if the data is anonymised. Care should be taken to separately organise consent for the acquisition, storage and use of information for research purposes.
- 2.7. One NCWNZ branch stated that: “There will be suspicion around how the information is to be stored, and in what format, who will have access, and how will those who access it be monitored, and how will the directors of these agencies be held to account. There will be scepticism on how successful sharing will be in terms of actual measurable outcomes”.

### **Factors that affect the implementation of protocols**

- 2.8. NCWNZ branches recognised that it is often a challenge for NGOs to train and support staff who are recording, using and sharing personal information of clients. They argued that more resources are needed by NGOs to implement best practice, even though requirements to do so are a standard part of government and NGO contracts. One NCWNZ branch stated that: “Most social service agencies are already stressed to the maximum in terms of time and resources, so there would have to be robust systems put in place to allow for workers in these service to collaborate and consult with members of other services without negatively impacting on time and resources needed for other important work”. Another NCWNZ branch considered that the system of contracting that requires social service agencies to compete with one another for contracts is not the ideal environment to encourage cooperation and collaboration in the sharing of information. Trust also needs to be re-established following breaches of client privacy by governmental organisations.

### **Exceptions to the principle of consent**

- 2.9. NCWNZ recognises that there are exceptions to the principle of the need for consent from clients when personal information is shared. Exceptions occur when there are safety issues, for example the risks of abuse of children if information is not shared among agencies providing social services, as well as risks when the information relates to intimate partner violence or criminal activity.

### Issues relating to control of information by NGOs

- 2.10. NCWNZ members considered that it was not only necessary for those providing personal information know why the information was needed and how it would be stored and used, but also that NGOs have a clear understanding of why information is needed and how it might be used. It must be possible for a social sector NGO to negotiate with government agencies about what information they will collect, store and share. As those closest to the clients whose privacy, personal interests and wellbeing is at stake, it is vital that they have a voice in issues relating to the collection, storage and use of data about their clients. They are the people who need to maintain the trust of people at vulnerable times in their lives.
- 2.11. At the same time, it is very important that both government agencies and NGOs are able to demonstrate that they are using protocols consistent with the Privacy Act. Ongoing training and education must be available to those recording and using personal information. It is also important that there is regular internal and external auditing of protocols relating to the storage, use and sharing of personal information.

### Sharing of information in the social sector

- 2.12. NCWNZ members stated that there are clear advantages to being able to access data recorded by agencies. The identification of patterns or trends could mean more specialist assistance for individuals or families. The sharing of information (with the consent of the person concerned) could avoid needless form filling, save time and avoid stress. Some members considered that the RealMe system could work well to avoid duplication of requests for personal information. However, clients are often concerned about the safety and security of their digitalised personal information.
- 2.13. These problems can be avoided if there are constraints on who can access the data and if clear decisions are made about exactly what information can be shared with whom within an agency or across agencies. Sharing of data should never be assumed. Systems can also be set up to tag data so that there is a record of who has accessed the information.
- 2.14. One NCW branch stated that: “The risk remains of an incomplete story being told by attention solely to the data that is digitally recorded. It is essential that there are records of specific needs and the situation of an individual so that they do not have to repeat descriptions of their circumstances to multiple staff members associated with different agencies or organisations.”

## 3. Cross-agency cross-sectoral work on wellbeing and data

- 3.1. NCWNZ is aware that consultation is currently occurring relating to the recording and sharing of information with respect to family violence and that Stats NZ are seeking feedback relating to

Indicators Aotearoa NZ.<sup>5</sup> The Treasury has been consulting on an Intergenerational Wellbeing Standards Framework. The consultation relating to investment for social wellbeing and the recording, storage and use of personal data in the social sector is closely related to the work being done by these other agencies. All these consultations are directed at seeking public input in the interests of identifying key principles and better practices, but these state agencies need to share insights and possible action arising out of these deliberative processes.

- 3.2. NCWNZ would like any documents produced out of the Your Voice Your Data Your Say consultation to address the relationship between work by the SIA in this field and related work on living standards, wellbeing and the recording of information, as well as issues relating to consent, storage and use of personal information. These consultations involve communication and collaboration among non-governmental organisations and between NGOs and government agencies. But it is vital that government agencies demonstrate that they are collaborating among themselves and integrating knowledge acquired about wellbeing and the collection, storage and sharing of personal information. NCWNZ considers that a cross-agency and cross-sectoral approach is necessary in the development of principles and policy relating to living standards, wellbeing and the acquisition of personal information that may be aggregated to monitor whether government aspirations for change are being achieved.
- 3.3. NCWNZ welcomes the opportunity to present this submission on these important topics.



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<sup>5</sup> Stats NZ – Tatauranga Aotearoa. Indicators Aotearoa New Zealand – Ngā Tūtohu Aotearoa  
<https://www.stats.govt.nz/indicators-and-snapshots/indicators-aotearoa-new-zealand-nga-tutohu-aotearoa/>