

June 2024

**To Statistics NZ**

Please find attached DPA’s submission on Modernising our approach to the 2028 Census discussion document

For any further inquiries, please contact:

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# Introducing Disabled Persons Assembly NZ

**We work on systemic change for the equity of disabled people**

Disabled Persons Assembly NZ (DPA) is a not-for-profit pan-impairment Disabled People’s Organisation run by and for disabled people.

**We recognise:**

* Māori as Tangata Whenua and [Te Tiriti o Waitangi](https://www.archives.govt.nz/discover-our-stories/the-treaty-of-waitangi) as the founding document of Aotearoa New Zealand;
* disabled people as experts on their own lives;
* the [Social Model of Disability](https://www.odi.govt.nz/guidance-and-resources/guidance-for-policy-makes/) as the guiding principle for interpreting disability and impairment;
* the [United Nations Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) as the basis for disabled people’s relationship with the State;
* the [New Zealand Disability Strategy](https://www.odi.govt.nz/nz-disability-strategy/) as Government agencies’ guide on disability issues; and
* the [Enabling Good Lives Principles](https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/), [Whāia Te Ao Mārama: Māori Disability Action Plan](https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan), and [Faiva Ora: National Pasifika Disability Disability Plan](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E544A3A23BEAECDCC2580FE007F7518/$file/faiva-ora-2016-2021-national-pasifika-disability-plan-feb17.pdf) as avenues to disabled people gaining greater choice and control over their lives and supports.

**We drive systemic change through:**

**Rangatiratanga / Leadership**: reflecting the collective voice of disabled people, locally, nationally and internationally.

**Pārongo me te tohutohu / Information and advice**: informing and advising on policies impacting on the lives of disabled people.

**Kōkiri / Advocacy**: supporting disabled people to have a voice, including a collective voice, in society.

**Aroturuki / Monitoring**: monitoring and giving feedback on existing laws, policies and practices about and relevant to disabled people.

## United Nations Convention on the Rights of Persons with Disabilities

DPA was influential in creating the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[[1]](#footnote-2) a foundational document for disabled people which New Zealand has signed and ratified, confirming that disabled people must have the same human rights as everyone else. All state bodies in New Zealand, including local and regional government, have a responsibility to uphold the principles and articles of this convention.

The following UNCRPD articles are particularly relevant to this submission:

* **Article 3 – General Principles**
* **Article 31 – Statistics and data collection**

‘1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:

a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;

b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.’

## New Zealand Disability Strategy 2016-2026

Since ratifying the UNCRPD, the New Zealand Government has established a Disability Strategy[[2]](#footnote-3) to guide the work of government agencies on disability issues. The vision is that New Zealand be a non-disabling society, where disabled people have equal opportunity to achieve their goals and aspirations, and that all of New Zealand works together to make this happen. It identifies eight outcome areas contributing to achieving this vision.

The following outcomes are particularly relevant to this submission:

* **Outcome 1 - Education**
* **Outcome 2 – Employment and Economic Security**
* **Outcome 3 - Health and Wellbeing**
* **Outcome 4 – Rights Protection and Justice**
* **Outcome 5 – Accessibility**
* **Outcome 6 - Attitudes**
* **Outcome 7 – Choice and Control**
* **Outcome 8 - Leadership**

# The Submission

DPA welcomes the opportunity to engage with Statistics New Zealand (Stats NZ) on the ‘Modernising our approach to the 2028’ Census consultation.

**DPA cautiously agrees in principle with the proposed shift away from a survey-based to a more admin-data-first approach for Census 2028, but we have several concerns which need to be addressed if the new approach is to be successful from a disability perspective.**

We rely on strong, reliable and accurate data about disabled people through the census and the associated NZ Disability Survey which runs every ten years.

Currently, there is no widely available disability data, including from many government channels to capture the statistics necessary to plan, for example, the level of disability support services required to meet the needs of an increasingly ageing population.

While the the NZ Disability Survey generates important disability data, a major downside is that it is only able to capture a snapshot of the disabled community every ten years.

There are other concerns around the Disability survey including that it relies on the Washington Short Set questions which fails to capture data from important sectors of the disabled community including from, for example, neurodiverse people.

If Stats NZ decides to proceed with an admin-data first approach to the census, the risk is that while it may capture some aspects of disabled people’s lives well, this new approach might still miss out or minimise other aspects of our lives altogether.

DPA does not want to see the continuation of the status quo either where there is always a lack of disability data as this means that our voices, experiences and health and wellbeing outcomes remain uncaptured. This lack of data means that disabled people are not present in system priorities, policies and accountabilities. This situation is only intensified for disabled Māori, Pacific and other intersectional communities.

The New Zealand Government, in failing to address this paucity of disability data is not meeting its obligations under article 31 of the UNCRPD to collect relevant statistical information on disabled people.

Successive New Zealand governments have also not encouraged a wider number of government agencies to meet their responsibilities under the New Zealand Disability Strategy 2016 – 2026 to collate disability data on a cross-government basis as well.

**This is why DPA recommends that Stats NZ gets the balance right in planning Census 2028 (and every census thereafter), particularly when it comes to meeting the needs of disabled people. The best way that Stats NZ can do this is through undertaking an extensive programme of co-design and engagement with disabled people, disabled people’s organisations (DPOs) including DPA, and the wider disability sector around the census.**

**Aligned with this, DPA recommends a strong cross-government approach disability data collection to ensure that more government agencies collect more timely disability related data as well, so that that collection should become more frequent and robust rather than just confined to the few agencies who do so at the moment such as, for example, Stats NZ, Ministry of Social Development, Whaikaha – Ministry of Disabled People, Health New Zealand Te Whatu Ora and Accident Compensation Corporation.**

This is needed, as apart from the regular surveys on disability employment (conducted by Statistics New Zealand), and disability support service figures from the disability funding agencies, there are no other frequent in-depth official statistical studies published on the status of disabled people around educational achievement, housing accessibility, transport provision or access to healthcare. When statistics on these facets of life for disabled people do appear, they are often contained in academic studies or one-off/infrequent government surveys from government agencies.

Ensuring a cross governmental approach to disability data compilation and its frequent publication would lead to Stats NZ’s proposed admin data first approach to the census being more successful.

However, if an admin first approach is brought in without a corresponding whole of government approach to disability data collection, then the current disability data deficits will remain the norm.

In this submission, we answer each of the questions outlined in the consultation document (barring the last one).

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| **Recommendation 1:** that Stats NZ gets the balance right for Census 2028 through undertaking extensive co-design and engagement with disabled people, disabled people’s organisations and the wider disability sector. |
| **Recommendation 2:** that a cross-government approach is taken to disability data collation to ensure that more government agencies are required to collect disability related data. |

## Q.1) ‘We trust Stats NZ to keep people’s information safe.’?

DPA agrees with this question as we recognise that Statistics New Zealand does its utmost to protect the data collated at every census and is prepared to investigate any alleged breaches involved in the collection of census data on its behalf.

However, while we welcome more government agencies coming onboard with their disability related data, this comes with caveats around how the data will be collated, stored and re-used, particularly when it comes from new government sources. This is an important consideration as New Zealand statistics show that disabled people are more likely to distrust public institutions (including government) than non-disabled people.[[3]](#footnote-4)

One of the principal reasons for disabled people distrusting government is a general anxiety around how their data will be used. According to the European Digital Rights Network, data privacy in the digital age is an important consideration for disabled people due to the discrimination and exclusion faced by our community. This is the case as any potential leakage or misuse of data by organisations can have adverse consequences including direct or indirect discrimination against disabled people.[[4]](#footnote-5)

DPA recommends that Stats New Zealand - if it does collect any new administrative data from any other government agencies whose statistics could prove useful for inclusion in future censuses and disability surveys from, for example, the Ministries of Housing and Urban Development, Justice, and the Department of Internal Affairs - be required to consult with disabled people and disability organisations through the co-design process before doing so.

It would be ideal to undertake any consultation on the above question during the second round of planned consultation on Census 2028. Doing so would enable assurances to be given that any new agencies included in the census process would undertake best practice when it came to the sharing of administrative information for the purposes of the census and other official information, thereby enabling the building of trust between the disabled community and relevant government agencies on this issue. It would also mean that wider public consent could be given to the sharing of more official information for the purposes of the census as well.

When discussing the potential use and misuse of individual data, it is important to note that in recent years there have been sporadic breaches of data privacy by various government agencies, all which have caused public anxiety.

Given all these factors, DPA recognises that Stats New Zealand has a duty to be more robust and diligent than ever about how it collects, stores and protects the data it receives in an age where malicious information hacks and thefts are becoming more commonplace.

DPA recommends that Stats NZ adequately invests in technology and programmes which enable the safe storage of individual data and applies the most up-to-date, rigorous data privacy protection and sharing standards and constantly reviews them, especially in the light of increased hacking activity.

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| **Recommendation 3:** that Stats New Zealand - if it proposes to collect any new administrative data from any other government agencies whose statistics could prove useful for inclusion in future censuses - be required to consult the public before doing so. |

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| **Recommendation 4:** that Stats NZ adequately invests in technology and programmes which enable the safe storage of individual data and applies the most up-to-date, rigorous data privacy protection and sharing standards and constantly reviews them. |

## Q.2) ‘Would be okay with Stats NZ reusing information (like tax or housing information) that has been given to other organisations so that Stats NZ can produce data, statistics, or research that would benefit our organisation and community.’?

DPA’s response to this question is that we agree with reusing information on the proviso that the recommended safeguards outlined in the first question around privacy, integrity and robustness are applied by Stats NZ.

As stated in the introduction, DPA is one of many Stats New Zealand customers which would benefit from having more disability related data available.

## Q.3) ‘People would prefer not to answer some questions in the census if Stats NZ can get the same information by reusing information already shared with other organisations.’?

## Q.4) ‘We want Stats NZ to ask different questions in the census, not questions other government agencies have already asked?’

DPA agrees with both these inter-related questions.

We are of the view that when Stats NZ plans each Census, it should ask itself the question as to whether it needs to include any question(s) which are already commonly asked by either yourselves or other government agencies as part of regular administrative surveys. For example, these would include questions on individual incomes and labour market participation that already form part of ongoing labour market surveys run by Stats NZ and income tax payment data supplied by Inland Revenue.

We outlined above the need for more disability related data to be generated, through both the census process and across government.

This is why we recommend engagement with disabled people and the disability sector specifically over the census and as to what questions would be most usefully contained within it from a disability perspective.

## Q.5) ‘What is most important to our organisation about the data and statistics produced through census?’

Earlier in this submission, we outlined the disability data deficits that currently exist, especially those within the census.

Despite the various shortcomings listed earlier, the NZ Disability Survey does provide an important source of information about the size and composition of the country’s disabled population.

Both our own and other disability organisations glean important information from the NZ Disability Survey and censuses that can be used in our systemic advocacy work with government around, for example, the state of disabled people’s health and wellbeing, income levels, access to services and supports alongside any other data considered worth collecting as part of the survey.

However, as we stated earlier, requiring more government agencies to regularly collect disability related data not only through the census but also through general agency and disability-community specific surveys would enable more comprehensive, relevant and, most importantly, more up-to-date official data on disabled people.

This would enable not only DPA but central and local government to have access to more frequent, timely and accessible information that is essential for better planning fand investment in a more accessible, inclusive society and better outcomes for disabled people.

**Q.6) ‘How would these proposed changes affect you and your information needs? (If answering from a community or group that might be impacted by the change, please let us know what that community or group is and what the impacts may be.)’**

If the proposed changes to the census are implemented well, it could present an opportunity for more timely disability data to be published on a regular basis, not just at the time of the census and/or NZ Disability Survey.

From an organisational standpoint, DPA finds it frustrating having to rely on NZ Disability Survey data which is up to ten years old and out of date. This means that not only us, but other government and non-government agencies constantly must rely on producing estimates of the disability population which maybe overestimates or underestimates.

Being able to access more reliable, timely demographic information on the disability population of Aotearoa would be helpful for our systemic advocacy work with both central and local government and other stakeholders.

DPA makes extensive use of all available disability data and we and our members and the wider disability community would benefit from a changed approach, provided that our caveats around data privacy and integrity are addressed.

**Q.7) ‘If Stats NZ, for the census, reuses data about people that has been shared with other organisations, what extra things (for example, protections and safeguards) would you like to see?’**

As covered above Stats NZ must sufficiently invest in technology and programmes which enable the safe storage of individual data.

It is also important that the public knows what statistical information is being collected from individuals and being passed onto Stats NZ.

DPA recommends that Stats NZ and other government agencies outline clearly on any official forms that any information provided by individuals or organisations could be passed to Stats NZ for either use in official statistics and/or Stats NZ approved research.

DPA additionally recommends on the same forms a privacy statement outlining that any data would be de-identified by Stats NZ or the government agency concerned before passed on for analysis, meaning that any personal details would be stripped off any data prior to doing so.

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| **Recommendation 5:** that Stats NZ and other government agencies outline clearly on any official forms that any information provided by individuals or organisations could be passed to Stats NZ for either use in official statistics and/or Stats NZ approved research. |

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| **Recommendation 6:** that Stats NZ and other government agencies outline on any official forms that any data would be de-identified by Stats NZ or the agency concerned before passed on for analysis, meaning that any personal details would be stripped off any data prior to doing so. |

**Q.8) ‘Does your organisation have any ideas about how Stats NZ might work with your community to collect data and statistics that cannot be found anywhere else?’**

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| **Recommendation 7:** that Stats NZ work with the disability community and sector in a co-design partnership to collect data and statistics on the following and any other topics which might be deemed relevant:   * Housing status of disabled people. * Access to everyday transport for disabled people. * Digital access for disabled people. * Needs of disabled parents/families/whānau/caregivers. * Access to health services including access to transport to get to health services. * Access to education. * Access to public buildings and the physical and built environment. * Number of disabled people participating in recreational, sporting, leisure and cultural activities. |

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1. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles> [↑](#footnote-ref-2)
2. <https://www.odi.govt.nz/nz-disability-strategy> [↑](#footnote-ref-3)
3. <https://www.stats.govt.nz/reports/measuring-inequality-for-disabled-new-zealanders-2018/> [↑](#footnote-ref-4)
4. <https://edri.org/our-work/why-privacy-is-particularly-crucial-for-people-with-disabilities/> [↑](#footnote-ref-5)