CRE–DH
**Centre of Research
Excellence in
Disability and Health**

SUBMISSION TO THE AUSTRALIAN BUREAU OF STATISTICS

In response to the 2026 Census topic consultation

In partnership with

THE UNIVERSITY OF MELBOURNE

THE UNIVERSITY OF SYDNEY

UNSW CANBERRA

RMIT UNIVERSITY

MONASH University

2026 Census topic consultation: Submission form

This document can be used to help draft a collaborative submission or if you prefer you can email your response back to us.

On completion, please check and submit your form via:

Email: census.content@abs.gov.au

Post: **2026 Census Topic Consultation**
Locked Bag 10
Belconnen ACT 2616

Online: Please visit the ABS Consultation Hub

Do you give permission for the ABS to publish your submission after the consultation closes? (Select one) *(Required)*

By selecting 'Yes, publish without my name, contributors' names and email addresses':

You give permission for the ABS to publish your responses, including information in attachments, about the data you want us to collect as well as which organisation(s) you are representing. Contact name(s) for you and any other individual(s) listed in the submission and your email address will not be published.

By selecting 'Yes, publish without my name, contributors' names and email addresses, and organisation details':

You give permission for the ABS to publish your responses, including information in attachments, about the data you want us to collect. The organisation(s) you are representing, contact name(s) for you and any other individual(s) listed in the submission and email address will not be published.

By selecting 'No':

No part of your submission will be published.

☒ Yes, publish without my name, contributors' names and email addresses

☐ Yes, publish without my name, contributors' names and email addresses, and organisation details

☐ No

Contact details

Please provide details of the best contact for this submission. These details will be used if we have any follow-up questions.

The [ABS Privacy Policy](#) outlines how the ABS will handle any personal information that you provide to us.

Contact name

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Do you wish to receive email updates on the outcomes of this consultation and at key points in the 2026 Census topic selection process?

☒ Yes

☐ No

Select the category that best describes you or the organisation you represent (Select one)

☐ Individual

☒ Academia/educational institution

☐ Australian government

☐ Business

☐ Community organisation

☐ Industry body/association

☐ Local government

☐ Non-government organisation

☐ State/territory government

☐ Other (please specify)

Has this submission been prepared in collaboration with any other individual(s) or organisation(s)?

We will not automatically send updates directly to these individuals or organisations. If they wish to receive email updates on the 2026 Census topic consultation process, they can subscribe to our [Mailing list](#).

☒ Yes – *please list name, organisation (if applicable) and email address in the section below.*

☐ No

Additional individual(s) or organisation(s)

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What information would you like the ABS to collect and produce statistics on?

If you have multiple topics and data needs, please complete a separate submission for each.

Please provide a brief summary of the information you would like the ABS to collect and produce statistics on.

Our submission is about adding the following question to the 2026 census (after question 27) which relates to identifying a broader group of people with disability based on limitation or restrictions in non-core activities:

Does the person have any limitation or restriction in one of the listed (non-core) activities?

Yes, always
Yes, sometimes
No

List of activities
Schooling
Employment
Health care
Reading or writing
Transport
Household chores
Property maintenance
Meal preparation
Cognition or emotion

Other ABS disability modules have established a solid base for collecting information about these non-core activities and our suggestion is taken from the Survey of Disability, Ageing and Carers (SDAC). In order to minimise the survey load, we do not propose to have individual questions for each of the non-core activities but instead whether there is limitation in at least one of the listed activities as presented above.

What topic does this information most relate to? (Select one)
You can find more information about Census topics in our Census dictionary.

☐ Aboriginal and Torres Strait Islander peoples

☐ Cultural diversity

☒ Health, disability, unpaid work and care

☐ Household and families

☐ Housing and homelessness

☐ Income, work, education and training

☐ Location and transport

☐ Population, including sex and gender

☐ Other (please specify)

To help us assess your submission, tell us why it is important that the ABS should collect and produce this information, including how you would use the data.

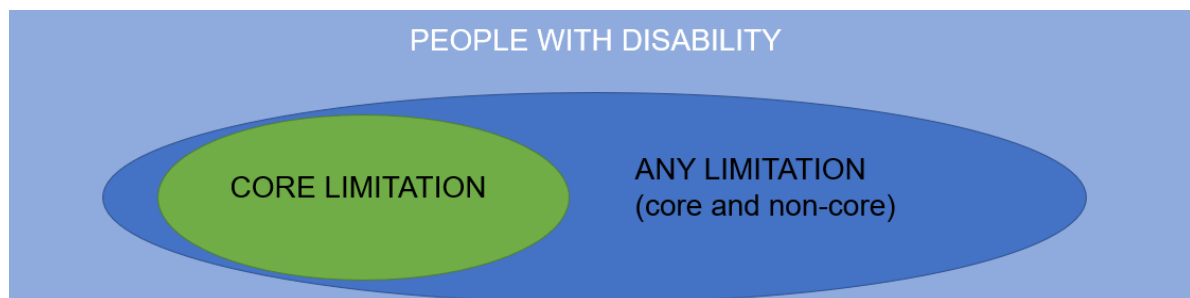*Please do not include any information which could identify you or another person.*

Assessment criteria:

The ABS uses a range of criteria to assess whether it includes topics in the Census or surveys. This includes the need for the data, the ability and willingness of the public to respond and how easy it is to collect the information. Your response to this question will help with our assessment regarding the need for the data. The specific criteria we will be looking for you to address in your submission are:

  a. *The topic is of current national importance.*
  b. *There is a need for data at the national level, and either the local level or for small population groups.*
  c. *There is likely to be a continuing need for data on the topic following the Census.*

What would our proposed question measure?

The current questions in the Census to identify people with disability (questions 24-27) only capture one-third of the population with a disability. Those questions identify Australians needing assistance in core activity (ASSNP), which is conceptually equivalent to individual who have profound or severe disability. We need to identify a broader group of people with disability. Our suggested additional question on non-core limitation would identify approximately 60% of people with disability.

Of all people with disability, represented by the light blue rectangle, the Census currently captures only the people conceptually described as having a profound or severe limitation (green oval). Our suggestion to add an additional disability question to the Census will instead capture approximately 60% of people with disability by including people with any limitation in everyday activities represented in the dark blue oval.

The need for legislative purposes

Understanding the needs of people with disability is crucial to policy development and monitoring, however **not being able to identify people with disability in administrative data** makes this very challenging. At present, since the majority of people with disability are not captured in the Census, **it is difficult to assess whether the Australian Government is meeting its obligations** and commitments to Australians with disability.

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (**UN CRPD**) the Australian Government is obligated to report on its progress on ensuring the "full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities". The Concluding observations on the combined 2nd and 3rd periodic reports of Australia by the UN Committee on the Rights of Persons with Disabilities highlighted that insufficient resources were allocated for the National Disability Strategy as well as a **lack of monitoring mechanisms**.

The Australian Government also has commitments to people with disability, as detailed within policy documents and legislation including Australia's Disability Strategy 2021-2031, Disability Discrimination Act 1992, and the forthcoming Australian Cancer Plan where people with disability are a priority group. Ongoing monitoring of these commitments and obligations can only be done if people with disability can be identified within the data.

The need from a budgetary perspective

There has been considerable investment in improving disability data and understanding their value for improving disability policy such as in the recent National Disability Data Asset (NDDA). Disability spending (e.g. within the National Disability Insurance Scheme and the Disability Support Pension) has been under scrutiny and is expected to continue to be monitored. Yet we have a limited understanding of the benefits of these programs mainly due to the inability to identify people with disability in the data. Because of this, we do not know whether these programs are reaching the people that needs to be reached or how effective they are. At present, the usefulness of the NDDA is compromised by its inability to identify the whole population of people with disability. Having a more comprehensive disability question in the Census would overcome this problem and allow better evaluation of the outcomes of disability spending within the budget.

Why can't we use alternative data?

Several surveys with disability information are available. The widely used annual Household, Income and Labour Dynamics in Australia (HILDA) Survey, which contains fairly comprehensive disability questions, has detailed information on many life aspects but is limited because it does not include people residing in institutional care, and as low representations of people living in remote areas and of First Nations peoples. The key survey for investigating questions that relate to people with disability is the Survey of Disability, Ageing and Carers (SDAC), which specifically provides detailed information on people with disability. **However, surveys, including SDAC, only include a sample of the population and are insufficient for examining the intersection of disability** and other characteristics such as Culturally and linguistically diverse (CALD) people, LGBTQIA+ people, First Nations people, or people living in remote areas.

Administrative data can help fill this gap. However, since administrative datasets only collect data about people that receive specific services, even the most comprehensive administrative datasets (e.g. DOMINO which includes people on welfare recipiency) include a portion of people with disability, while some have no disability identifiers at all.

Recently, linked administrative datasets (e.g. MADIP, NDDA) have become more readily available to researchers, allowing a wide range of research questions to be examined. In our research on people with disability, many of these datasets need to be linked to Census data so that we can identify people with disability before we can monitor their outcomes and the effectiveness of disability policies and programs. However, since the Census currently only identifies people with disability who have core limitations, it only identifies one-third of the Australian disability population and limits research efforts. Adding a question to the Census that will more comprehensively capture people with disability will improve the accuracy of the linked datasets and research on people with disability.

How would we use the data?

Identifying a broader population of people with disability would help evaluate policy and monitor progress in reducing inequalities between people with and without disabilities. This is essential for the Australian Government to meet its obligations under the UNCRPD. Furthermore, given that the proportion of people with disability is increasing as the Australian population ages, the value of identifying a broader group of people with disability will increase over time.

The addition of the question would be extremely valuable for several research purposes especially when linked with other datasets. For example, when combined with death registry data, researchers would be better equipped to investigate research questions that relate to mortality and causes of mortality. For instance, examining whether people with disability have higher rates of mortality from suicide. Another example would be investigating whether receiving NDIS funding reduces mortality for people with disability. Both of these examples require comprehensive detection of people with disability, but the currently restricted measure of disability in the Census makes this research very challenging.

With better disability questions in the Census linked to other data, we could start investigating potential inequalities in cancer risk and mortality between people with and without disability, how much earlier or later are people with disability diagnosed with cancer and would help understand what interventions could help reduce those inequalities.

Another example in work we are currently undertaking is assessing the coverage of COVID vaccinations for people with disability, which is done using AIR MADIP, the MADIP dataset linked with the Australian Immunisation Register (AIR). Despite the richness of the available data and several markers for disability within MADIP, drawing conclusions on the adequacy of vaccination coverage for people with disability is proving challenging given that each marker has its own limitations. A broader definition of disability in the Census would help to overcome these

challenges so that we could more accurately assess the effectiveness of emergency responses and public health interventions for people with disability.

In summary, there is simply no national data capturing all people with disability. One NDDA case led by the Centre of Research Excellence in Disability and Health has shown how linked data have been helpful to identify people with disability but has also shown that many people are missed out. It will be difficult to understand the value for money of disability policies or to comply with our legislative obligation of monitoring inequalities between people with and without disability without a good indicator for people with disability.

Our suggested additional question would not require extensive processing or coding nor does it require multiple questions/ large number of response categories. It is also our understanding that the question is simple enough and questions on non-core activity limitations have successfully been used in other ABS surveys. Therefore, it is our opinion that the addition of this single question to the Census would be an efficient and simple measure to fill in a much needed data gap.

For what purpose(s) will you use the data? (Select all that apply)

☐ Resource allocation for programs and policies

☐ Planning, development, monitoring and evaluation related to programs, policies and service delivery

☒ Research

☐ Journalism/media

☐ Other (please specify)

What is the smallest area or geography required to effectively use this data? (Select one)

Common geographies or area boundaries:

- *Mesh Block (Residential block/rural area)*
- *Statistical Area Level 1 (Neighbourhood/rural district)*
- *Statistical Area Level 2 (Suburb or locality)*
- *Statistical Area Level 3 (Part of region)*
- *Statistical Area Level 4 (Region)*
- *Greater Capital City Statistical Areas (Capital city broad regions)*
- *Significant Urban Areas (Large urbanised areas)*
- *Urban Centres and Localities (Cities and towns)*
- *Indigenous Locations (Aboriginal and Torres Strait Islander communities)*
- *Remoteness Areas (Remoteness Classification)*
- *Local Government Areas*
- *State Electoral Divisions*
- *Commonwealth Electoral Divisions*

More information is available on the [Census geography glossary](#) page.

☐ National

☐ State/territory

☐ Statistical Area Level 2 (suburb or locality)

☒ Statistical Area Level 1 (neighbourhood/rural district)

☐ Local Government Area

☐ Don't know

☐ Other (please specify)

Additional information

Would you like to tell us anything else about your submission?

Please do not include any information which could identify you or another person.

We would like to use this opportunity to suggest releasing a disaggregated version of the Core activity need for assistance (ASSNP) variable since answers to each of these questions are individually very valuable. We ask ABS to consider providing these data items separately, at least in the more secure data dissemination channels such as MADIP, to allow advanced data users to explore the Census statistics to the full potential.

For example, with linked data we could assess whether some individuals with similar levels of functioning are missing out and not being supported by the NDIS. Such data would also help monitor outcomes of the Australian Disability Strategy especially with linked data (where SDAC does have sufficient power).

You can also attach documentation to support your submission. Please make sure your file is under 25MB.

Please note if you have provided consent for the ABS to publish your submitted information, this includes information provided in attachments.

Thank you...

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References

NDDA test case - Methodology Paper Identification of people with disability in linked administrative data 9 December 2021 Dr Zoe Aitken, Dr Nicola Fortune, Ms Lauren Krnjacki, Dr Samia Badji, Dr George Disney, Professor Anne Kavanagh