

# National Disability Strategy Implementation Reference Group

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2016 Census Submissions  
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Dear Australian Statistics Advisory Council (ASAC)

## **RE: 2016 CENSUS TOPICS**

Thank you for the opportunity to respond to the call for submissions on topics for the 2016 Census.

This submission is being prepared by the National Disability Strategy Implementation Reference Group (NDSIRG). The Australian Government has established the NDSIRG, comprising of representatives from the National People with Disabilities and Carer Council (NPWDACC) as well as representatives from the National Disability Organisations, to provide the Australian Government with advice on the implementation of the National Disability Strategy.

## **BACKGROUND:**

### *The Census:*

The Census of Population and Housing is a descriptive count of everyone who is in Australia on one night, and of their dwellings.

The Census of Population and Housing is the largest statistical collection undertaken by the ABS and one of the most important. Its objective is to accurately measure the number and key characteristics of people who are in Australia on Census Night, and of the dwellings in which they live.

This information provides a reliable basis for estimating the population of each of the states, territories and local government areas, primarily for electoral purposes and for planning the distribution of government funds.

Census data are also used by individuals and organisations in the public and private sectors to make informed decisions on policy and planning issues that impact on the lives of all Australians.



Everyone in Australia is legally required to complete a Census form, to ensure that our Census data give an accurate and complete picture of our nation.

The Census has credibility and status. It is the key to informed planning; yet it effectively excludes the 1 in 5 Australians who have a disability. It tells us nothing about our lives or where we live. It does not give an accurate picture of disability in Australia where disability is now one of the most important social assistance issues in the public domain. It asks the wrong questions based on an outmoded and fading idea of support.

### **DISABILITY AND CENSUS:**

We note that the ABS has flagged that it is reviewing 2011 Census Household Form Questions: 20, 21, 22 and 23. These questions are:

- Q20: Does the person ever need someone to help with, or be with them for, self-care activities?
- Q21: Does the person ever need someone to help with, or be with them for, body movement activities?
- Q22: Does the person ever need someone to help with, or be with them for, communication activities?
- Q23: What are the reasons for the need for assistance or supervision shown in question 20, 21 and 22.

This review is welcome as NDSIRG believes that the current questions do not meet important priorities for disability. The 2011 Census did not identify many people who are deaf, blind, have an intellectual, physical or any other disability, unless they receive support with everyday basic care needs from other people. These questions also do not assist with identifying the extent of people with a disability at local area level.

The Census does ask questions about whether we ever have a carer to help with self-care, or communication activities. It will also ask whether people are unpaid carers.

It is important to know about people that receive and provide care, but interventions by other people aren't the only way that disability is experienced.

There is a large diversity of people with disability who do not receive care from others but require accessible communities, infrastructure, information and equipment in their daily living. In ignoring people with disability who do not need assistance, the Census does not contribute to good planning or future management for an inclusive society by Government, business or the community. They operate on a very outmoded understanding of support and assistance.

The lack of a direct question about personal experience of disability is problematic. It ignores disability as a citizen identity, suggests that disability is only ever important to the extent that it 'impacts' on others and compounds a lack of hard knowledge that we have about disability in Australia.

## THE NATIONAL DISABILITY STRATEGY

Current data from the Census, limits our knowledge about people who may not need daily assistance, but still benefit from work under the National Disability Strategy to remove barriers in areas like equipment, spaces and places, communication access or alternative formats, so we can manage independently in the first place.

The *2007.0 - Census of Population and Housing: Consultation on Content and Procedures, 2016 ABS discussion paper* states that census data on this topic are used in the calculation of performance indicators for COAG reporting on the National Disability Agreement (NDA); however, we note that the NDA is not the only, or even the primary, intergovernmental vehicle for disability policy in 2013.

There is a Council of Australian Governments (COAG) agreed National Disability Strategy, which seeks to drive intergovernmental work across Australian Government, State, Territory and Local Governments in areas such as employment, infrastructure, transport, communications, education, mainstream services and allied health.

The National Disability Strategy 2010-2020 sets out a ten year national policy framework for improving life for Australians with disability, their families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development. This new approach will assist in addressing the challenges faced by people with disability, both now and into the future.

The Commonwealth, State and Territory and Local Governments have developed the Strategy in partnership under the auspices of COAG.

The Strategy is the result of a large nation-wide public consultation process, involving more than 2,500 people and was formally endorsed by COAG on 13 February 2011.

The Strategy sets out six priority areas for action to improve the lives of people with disability, their families and carers.

These are:

- **Inclusive and accessible communities**—the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.
- **Rights protection, justice and legislation**—statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.
- **Economic security**—jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
- **Personal and community support**—inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support.
- **Learning and skills**—early childhood education and care, schools, further education, vocational education; transitions from education to employment; life-long learning.
- **Health and wellbeing**—health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

The National Disability Strategy will guide public policy across governments and aims to bring about change in all mainstream services and programs as well as community infrastructure. It is the first time the Commonwealth, State and Territory Governments have agreed to such a wide ranging set of directions for disability.

Planning under the National Disability Strategy requires information about the prevalence of disability and the prevalence and experience of community barriers to support effective national decision making. This information is not available from alternative data sources. The SDAC is a useful survey but it is a household survey and does not provide granular local area data.

### **WHAT'S MISSING FROM THE CURRENT TOPICS?**

The previous questions on need for assistance provide an inaccurate picture of the extent of disability and do not provide useful management information for the Australian Government, the States and Territories, Local Governments, business or the third sector about the demand for mainstream services needed to implement the National Disability Strategy.

They do not support planning for policy areas identified under the National Disability Strategy and they provide only limited information about personal and community support as not everyone receives assistance in the form of interventions by another person.

The previous questions also provide only limited information to support the implementation of the DisabilityCare Australia, which is a multi-year, multi-billion dollar legislated social assistance program with bipartisan support.

The questions do not support a good understanding of the broader group of people with disability outside those in the funded category of the scheme who are the focus of the initial launch sites only.

In order for Australia to meet its obligations of the National Disability Strategy and to enable it to plan for the future there is need for local area data on people who have a disability, but do not require daily assistance.

The previous questions do not provide good whole of nation information about the extent of the disability market which is desirable if business is to move from seeing disability as a customer service rather than a compliance issue.

They do not allow easy and compelling calculations on the total value of the disability market to the economy which might be used to form a convincing case for action on disability employment in the skills shortage, for addressing market gaps like accessible tourism or for industry planning in areas like housing, where there is active discussion about the need for universal design principles to be included in the Building Code of Australia under the auspices of the Australian Network for Universal Housing Design.

## **PROPOSED QUESTIONS FOR 2016:**

In light of the above, the NDSIRG recommends retaining only one question on 'need for assistance' and replacing three of the remaining questions with the two questions as below:

### **Q1: Does the person have a disability, impairment or health condition that results in changes to appearance, bodily, mental, emotional, sensory, social or learning functions?**

*This question is drawn from the DDA and would capture a wide range of people who experience disability. It addresses current and future need under the National Disability Insurance Scheme (NDIS) as well as other parts of the informal and formal support systems.*

### **Q2: Does the person have a disability, impairment or health condition that results in barriers to accessing services, products, places or spaces:**

**[and include a tick box list of barriers such as to employment, health, transport, education, buildings, recreation, housing, information, telecommunications, etc.]**

*This question seeks to identify whether people experience barriers to mainstream systems for planning under the National Disability Strategy. It will support planning by all three levels of Government, business and the third sector.*

*This question seeks to provide valuable high level data on broad Australian community views on barriers to access, noting more detailed and disaggregated data on specific barriers can be collected elsewhere.*

## **SUITABILITY CRITERIA**

We note that a set of criteria is used to judge the suitability of topics for a Census. The questions included in the Submission Form relate to these five criteria, which are:

- **the topic is of current national importance**

*Topics selected for a Census must relate to an issue that is of current national importance. There must be a demonstrated need for the Census data for policy development, planning and program monitoring, or for the provision of data on this topic as an electoral or legislative requirement.*

*Submissions proposing the inclusion of new topics should clearly indicate the value of the information by showing the uses to which it will be put. Submissions should also spell out the implications of the topic not being included in the Census.*

Response:

The topics are of national importance and merit inclusion in Census 2016. They support policy frameworks developed by 8 State and Territory Governments, the Australian Government and Local Governments as well as a multi-year, multi-billion dollar investment in social security architecture legislated by both houses of the Australian Parliament.

The proposed Q1: Supports the National Disability Strategy and the National Disability Agreement and the Enhanced Service Offer underway in the launch sites. The National Disability Insurance Scheme is a multi year, multi billion dollar investment program legislated by both Houses of the Parliament and agreed by a number of First Ministers. In NSW, the largest State in the Commonwealth, the scheme is funded out to 2018/19.

The proposed Q2, supports the National Disability Strategy. The National Disability Strategy 2010-2020 sets out a ten year national policy framework for improving life for Australians with disability, families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development. This new approach will assist in addressing the challenges faced by people with disability, both now and into the future. It supports a social model of disability.

- **there is a current need for data on the topic for small population groups and/or at the small area level**

*As the Census covers all households, it can produce information at the small geographic area level or about small population groups, and enables cross-classification with other characteristics collected in the Census.*

*Submissions proposing the inclusion of new topics or supporting existing topics, should clearly show why this information is currently needed at the small area level or for small population groups.*

*Information required for broad geographic areas only (e.g. at the state or national level) may be better obtained by other means (e.g. sample surveys) depending on the detail of the cross-classification required. If the need is restricted to information about a few specific small areas, other collections or methods could be more appropriate.*

Response:

Yes there is a current compelling and ongoing need for small area data.

For instance, the NDS includes a priority for inclusive and accessible communities—the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life. The current SDAC data cannot provide an indication of current and future need in a community within a state such as within a remote community or in northern Tasmania which might assist planners to identify the need for universally designed infrastructure or housing in those areas. Disability is not evenly spread across Australia – there are known pockets of prevalence in indigenous communities and in other communities characterised by social and economic disadvantage. The ABS cannot meet this information need without questions in the Census.

- **there are no other suitable alternative data sources available for the topic**

*Consideration should be given to whether data are available from other sources. For example: similar or surrogate data may be collected by another organisation, there may have been surveys already conducted by the ABS, or the data may be available from administrative records.*

*The ABS produces an extensive range of information from economic censuses and surveys, administrative sources, and a comprehensive program of household surveys. While the ABS household surveys are not able to collect the detailed information that can be obtained from the Census for small groups or small areas, there are other advantages associated with interviewers collecting the data rather than the self-enumeration method used in the Census.*

*For information on all data published by the ABS, users should refer to the ABS web site at [www.abs.gov.au](http://www.abs.gov.au).*

Response:

Deficiencies in disability data sources are well known. For instance the Australian Institute of Family Studies, reflects on SDAC and the Census and tells us that

“While the 2006 Census data can be used to fill some of the gaps resulting from the sample size limitations of the SDAC, the Census itself also has its limitations. The 2006 Census included just one question that identified people with a profound or severe disability. The identification of people with a profound or severe disability based on a single question is not as rigorous as other surveys such as SDAC. Thus, it is likely to have underestimated the number of people with a profound or severe disability (Productivity Commission, 2010). It was also not possible to use the Census to identify older parents who looked after their adult children with a milder disability”<sup>1</sup>.

By implication, AIFS identifies a key risk for DisabilityCare Australia scheme as well as the NDS.

The current ABS SDAC is a household (sample) survey. It is not comprehensive. It does not survey every Australian or every part of Australia.

SDAC 2009 had a sample of over 64,000 persons (with and without a disability), from both private and non-private dwellings. The 2009 SDAC was designed to provide reliable estimates at the national level and for each state and territory. The SDAC does not seek to provide useful management information at the local government area level and therefore does not support local government work under the NDS.

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<sup>1</sup> <http://www.aifs.gov.au/institute/pubs/carers/carersb.html>

- **the topic is suitable for inclusion in the Census**

*In the Census, information is collected by 'self-enumeration' with each household being required to fill in a Census form. Self-enumeration, and the need to ensure the large Census operation is conducted as efficiently and effectively as possible, impose certain constraints on the type of topics included. It is vital to minimise the reporting burden on households and control Census costs. Questions asked on the Census form need to be readily understood by all householders.*

*Topics that require detailed explanation to ensure accurate answers are unlikely to be answered correctly. Research has shown that people often do not read the explanations that accompany questions. Questions that are controversial or could cause adverse reactions may also not be answered correctly. Such questions could also affect the quality of other responses. Information about these types of topics may require interviewer based collection methods.*

Response:

Yes and the topics are clearer and more suitable than the current topics.

*Simpler*

We are proposing to reduce 3 questions to 2 and are using clearly understood definitions based in the Commonwealth DDA and the National Disability Strategy

*More inclusive*

There is no nationally accepted definition of "disability" or method of categorising the severity of different types of disabilities in Australia so the questions encompass disability, impairment or health condition. We also note that impairment is part of the World Health Organisation definition for disability.

*Less confusing:*

The current questions are confusing, miss large parts of the disability population and are open to misreading. They are also built on old models of support.

Q20: Does the person ever need someone to help with, or be with them for, self-care activities?

Issues: This question invites a perverse outcome. A person whose house did not include an accessible toilet might answer yes, while a person with exactly the same level of disability but with an accessible bathroom and a hoist might answer no.

Q21: Does the person ever need someone to help with, or be with them for, body movement activities?

Issues: What is the continuum of things which can be described as body movement activities? Does this cover people in wheelchairs who can manage independently and push or transfer themselves? Why is the question framed in terms of assistance from someone else?

It invites a perverse outcome. A person using a wheelchair who is being inappropriately lifted by a person could answer yes, but a person with the same level of disability but with a wheelchair hoist would answer no.

Q22: Does the person ever need someone to help with, or be with them for, communication activities?

Issues: This question invites an ambiguous or contradictory reading – most communication activities involve being with someone else.

It also again invites a perverse outcome and is based on a pre-technological conception of disability support. This question would mean that a person who is blind and has someone read them a book would answer yes, while another person who is blind borrowing an audio book or downloading one over a specialised device would answer no.

These personal intervention based questions will become steadily more outmoded with new technology such as high speed broadband. For example, is someone being 'with' a person if they are online?

- **there is likely to be a continuing need for data on the topic in the following Census**

*The need for time-series data has traditionally been an implicit component of the selection criteria. There should be an appropriate balance between the two needs of relevance and time-series. If both are considered to be fulfilled (i.e. the topic is currently relevant and likely to remain relevant for future censuses) then there will be a good case for retaining or including the topic. However, if one of these is not assessed as being fulfilled (i.e. while there is comparable time series data from previous censuses the topic is no longer relevant in modern society, or while the topic is very relevant for the current times it is unlikely to remain relevant in the future) the topic is unlikely to be recommended.*

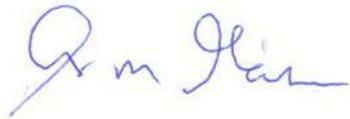
Response:

The Commonwealth Disability Strategy runs out to 2020 and the NDIS (DisabilityCare Australia) is legislated and has bipartisan support meaning that key policy work on disability is likely continue for many years to come. The Intergenerational Reports indicate that our population is ageing with the baby boomers starting to retire in 2012 while the 2020 summit showcased ongoing impacts from disability and comorbidity out to 2050. Commonwealth State/Territory Disability Agreements have been in place for over two decades. Disability will be on our agenda for many decades to come.

NDSIRG would also like to take this opportunity to reiterate that for many Aboriginal and Torres Strait Islander people there is no traditional word for 'disability' as such it is important for questions about disability to be written in a way to enable Aboriginal and Torres Strait people with disabilities to respond.

Once again, thank you for the opportunity to provide a submission. We hope that the Australian Statistics Advisory Council (ASAC) will decide to provide a more accurate representation of Australian citizens with disability in the 2016 Census.

Yours sincerely



Ms Lesley Hall  
Co-Chair  
June 2013



Dr Rhonda Galbally AO  
Co-Chair