

National Disability Strategy Implementation Reference Group

C/- Disability and Carers Policy Branch
Department of Families,
Housing, community Services
and Indigenous Affairs
GPO Box 7576
Canberra Mail Centre ACT 2610

E-mail: ndsirg@fahcsia.gov.au

Ms Cathy Etherington
Assistant Director
Disability and Mental Health Section
Australian Bureau of Statistics
Locked Bag 10
Belconnen ACT 2616

Email: disability@abs.gov.au

2015 Survey of Disability Ageing and Carers

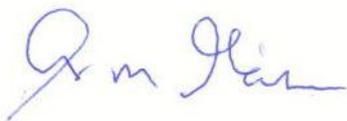
Dear Ms Etherington

Thank you for the opportunity to respond to the call for submissions on the 2015 Survey of Disability Ageing and Carers.

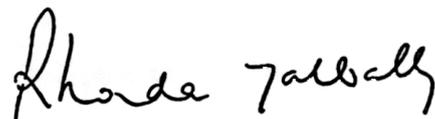
The attached submission has been prepared by the National Disability Strategy Implementation Reference Group (NDSIRG). The NDSIRG has not structured its response according to the questions provided in the discussion paper rather it offers a number of overarching comments.

Thank you for the opportunity to provide a submission to the discussion paper. We would be happy to discuss the contents of this submission with you further.

Yours sincerely



Ms Lesley Hall
Co-Chair



Dr Rhonda Galbally AO
Co-Chair

7 June 2013



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2015 SURVEY OF DISABILITY AGEING AND CARERS

SUBMISSION BY THE NATIONAL DISABILITY STRATEGY IMPLEMENTATION REFERENCE GROUP

INTRODUCTION

The Australian Government has established the National Disability Strategy Implementation Reference Group (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

NDSIRG would like to provide its understanding of the discussion paper on the 2015 Survey of Disability Ageing and Carers (SDAC). The Australian Bureau of Statistics (ABS) is commencing the development for the 2015 SDAC and is seeking feedback from stakeholders about the content of the survey, to ensure that questions are prioritised, relevant and the subsequent data can be used for its intended purpose.

The ABS has noted that the 2015 SDAC will be the seventh in a series of regular disability, ageing and carers' surveys, which have been conducted triennially since 2009. The aims of the survey are to:

- measure the prevalence of disability in Australia;
- measure the need for support of older people and those with a disability;
- provide a demographic and socio-economic profile of people with disabilities, older people and carers compared with the general population; and estimate the number of and provide information about people who provide care to older people and people with disabilities.

The most recent SDAC was conducted during 2012-2013, with the first release of data scheduled for 13 November 2013.

COMMENTS

Current SDAC

NDSIRG notes that 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.

Indigenous Disability Data

NDSIRG acknowledges that the ABS released the prevalence rates of disability for Aboriginal and Torres Strait Islander peoples from the 2009 SDAC. NDSIRG would 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 Islander people with disability to respond.

Link to the Census

NDSIRG notes that the 2009 SDAC did not seek to provide useful management information at the local government area level and therefore did not support local government work under the National Disability Strategy and considers this information shortage is best captured through specific questions in the Census.

Given that the Census questions are being reviewed, it is hard to suggest questions for the 2015 SDAC in isolation. For example, if disability questions were taken out of the Census altogether, then more questions will be required in SDAC. Without knowing future Census questions on disability, it is very difficult to provide specific constructive SDAC questions.

2015 SDAC Discussion Paper

Overall the range of issues covered by the proposed 2015 SDAC are satisfactory and the ensuing data will provide a good evidence base for research, policy formulation and service delivery purposes. However, there are some issues outlined below the ABS might like to consider.

General Comments

NDSIRG suggests that the 2015 SDAC questions are reframed to move away from an outmoded concept of people with disability being dependent on care - to ones that address barriers to full participation. For example, moving away from language concepts such as respite/care to active participation as citizens. The SDAC questions need to reflect this shift to ensure good data on community participation and the barriers to this.

As systems become more flexible with what people can do with disability support, the notion of measuring formal respite becomes more difficult. Any time a person with disability is being supported by someone other than the primary carer it could be measured as respite. This means that the use of the term 'respite' as a service category is problematic as responses are dependent on perspective rather than type of service, for example; community activities such as day support from a carer perspective are respite but from the person requiring support it is about getting support to pursue activities, meet friends, and have meaningful interaction with others. NDSIRG therefore recommends that respite is measured in first and second order goals: The first to do physical activity and meet friends (e.g. gym program), and second order to provide respite.

The word 'burden' is inappropriate and should not be included in the 2015 SDAC and other documentation. How the role of carers is portrayed in the 2015 SDAC needs to be done carefully to acknowledge the effort and emotional nature of caring without connotation or judgement of the person being cared for, or the need the person has for assistance. Training of interviewers needs this taken into account.

In addition, NDSIRG believes the 2015 SDAC should capture demographic data that allows analysis on specific populations, for example, how many women with intellectual disability from non-English speaking background communities have difficulty in accessing public transport.

It is understood that the ABS will not include specific questions around DisabilityCare Australia for the 2015 SDAC as the data is limited to the launch sites and would therefore provide a very small sample within those specific areas.

NDSIRG would like the ABS to consider the impact of DisabilityCare Australia in terms of the paradigm shift in the way people with disability will be gaining choice and control in the future.

There appears to be an alignment of most topics in the SDAC to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articles. If there was a direct match then the SDAC would include access to justice and it is very important to include people in prisons. In addition, it would include rehabilitation and habilitation which could give valuable information on people transitioning from health systems to community and disability support systems. There is a lot of anecdotal, research and media reporting on a significant percentage of prison populations having disability.

It is understood that the ABS has a separate short questionnaire relating to people in jail and is used to estimate prevalence. However, NDSIRG considers it invaluable to include information around people with disability in prisons in the 2015 SDAC. In addition, NDSIRG would like to see questions around juvenile detention centres, the numbers of young people with disability in these centres and the characteristics.

NDSIRG believes there is a need to measure community attitudes, in particular around discrimination

DISABILITY

Identification of Disability

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 and/or health condition/s. In addition, impairment is part of the World Health Organisation definition for disability.

Using data from the Survey of Disability, Ageing and Carers ("SDAC's"), 12% of the population identified themselves as having a hearing impairment. Within the Household Labour Dynamics of Australia ("HILDA") survey dataset by Watson and Wooden (2002), only 4.2% of people identified themselves as having a hearing impairment. Both figures are markedly lower than the population data produced by David Wilson and friends (1992) which found that 22% of people aged over 15 years had a hearing impairment. This demonstrates **that it is vital to understand the different data collection methods used** in both of the above studies, as it impacts significantly upon the number of people reporting a hearing impairment. For example, SDAC asks people to report if they have a condition which results in restrictions, such as communication difficulties, whereas HILDA took the approach of asking people first if they had a disabling condition before being asked to specify which one.

Throughout the discussion paper the use of language when identifying or describing people with disability is out-dated and should be changed, especially if it appears in the 2015 SDAC, to reflect current language.

1. Language around acquired brain injury (ABI). Referring to ABI as 'damage' has a negative connotation. The correct term is acquired brain injury.
2. NDSIRG is aware that there is a tension between maintaining validity/consistency of data collection as balanced with updating language and measures within the survey, however there are instances where this may be required. For example, language around 'nervous or emotional condition' and 'mental illness or condition requiring supervision'. NDSIRG would suggest using alternative language such as 'mental health or psychosocial condition requiring care and support'.
3. Language around 'impairments in mental functioning' – NDSIRG is unsure whether this refers to cognitive impairments and should be clarified in the 2015 SDAC.
4. In terms of identifying disability, the current tools aren't considered an adequate capture of whether someone has a disability. In some ways it is too broad – for example, someone experiencing significant symptoms of menopause could fall under this definition. In particular, it is undesirable to have inherent assumptions in the data that someone with a certain identifier will have a specific level of impairment.
5. It is important to capture people with psychosocial disability.
6. It is important to capture all people with hearing loss who use hearing aids. This is a different to people who may have their eyesight corrected through prescription glasses, as hearing loss has more disabling consequences.

Long-term Health Conditions

It should be noted that living with long term health conditions as a heading is broader than Alzheimers / dementia.

NDSIRG agrees that it is important to capture dementia in the 2015 SDAC and that more rigorous measures/tests for dementia are warranted.

Self-Perception of Health and Wellbeing

NDSIRG considers it important to capture this data to better understand the success of the implementation of the UNCRPD. In addition, the data is used in discussions around persons' life satisfaction, feelings of safety, need for education programs/curriculum on inclusion and bullying.

Need and Receipt of Assistance

NDSIRG believes this should be **reframed** to support the paradigm shift of the National Disability Insurance Scheme – DisabilityCare Australia. With the introduction of DisabilityCare, which has as a central tenet 'control and choice', it is pertinent to have a question on whether it is a provider of choice – particularly in relation to formal service providers.

In the discussion paper the ABS uses the term 'help'. NDSIRG considers this term as condescending and would like to have it replaced in future documentation and the SDAC with 'assistance'. The ABS should also consider changing the term 'supervision' to 'support'.

NDSIRG would appreciate the ABS reviewing the 'daily activity areas' for e.g. 'household chores', what is the difference between activities of daily living and self-care; what is covered in reading and writing as opposed to communication?

It would be useful to have some questions included in the 2015 SDAC which address the additional care requirements for children/youth with disability due to their disability, as opposed to the significant amount of care required for any child from their parents.

NDSIRG has some concerns about the proposed rotation of data, as 6 years between some data sets is too long.

A major area that is not included in the 10 areas listed is the need for financial assistance – this includes a range of activities such as getting money out of a bank (which these days could include supermarkets), paying bills, or even more help in actually managing the person's total finances – which is particularly true if the person has cognitive dysfunction.

Many carers spend considerable time and effort on these matters. When DisabilityCare Australia and other older people's packages are individualised this will have the potential to become quite an issue for both people with disability and for their carer. It could also be very useful information for potential service providers as they move to providing more relevant services to meet the needs of people with disability and their families.

Rotation of Questions

NDSIRG believes that the ABS' proposal to rotate some questions to be only asked every second iteration of SDAC would be problematic and cause disruption to data collection.

Satisfaction with Formal Assistance

NDSIRG believes this should be reframed to support the paradigm shift of the National Disability Insurance Scheme – DisabilityCare Australia.

Transport

NDSIRG considers it useful to capture data around the barriers to using transport. SDAC currently collects data about whether the person has a driver's licence, how often they drive, public transport concession cards, their ability to use public transport, barriers to using public transport, places they have travelled in the previous fortnight, and the main form of transport used to reach the most recent place travelled to.

However, information about unmet need is not collected. Given the Accessible Public Transport Jurisdictional Committee (APTJC) has indicated that there is zero data showing unmet need for school buses, there needs to be a way to collect information showing potential demand/unmet need. Certainly parents might have 'equivalent access' options e.g. a taxi but this ignores the community inclusion aspect referred to in the 2007 review of the *Disability Standards for Accessible Public Transport 2002* (DSAPT). This review indicated that more questions/information relating to transport should be collected.

NDSIRG believes it is important to ensure that questions on accessible public transport are included as the data will provide a way to find out if people have been unable to go somewhere or do something because of a lack of transport.

Aids

NDSIRG considers it important to **retain** the mobile phone question. It is understood that people with disability experience significant social isolation/disconnection with the community and this measure would provide data to assist with the measurement of this issue.

In relation to access and use of phone communication tools and home access to Internet, the issue is not whether these are commonly used rather it is about finding out what groups need this and can't access it, for e.g. people with intellectual disability or in group homes or residents in residential aged care facilities. Also whether if they do have it, is the cost prohibitive? And are they replacing the need for other specialised tools and equipment?

Participation in Social and Community Activities

NDSIRG considers it important to frame this section in accordance with the UNCRPD. In addition, questions regarding civic participation such as voting should be included.

It would be useful for the 2015 SDAC to ask specific questions about what stops people from leaving the house, contacting friends etc. to find out what are environmental barriers, personal need issues or social and attitudinal barriers.

Housing

NDSIRG agrees to **retain** this topic from the 2015 SDAC.

Feelings of Safety

NDSIRG agrees to **remove** this topic from the 2015 SDAC as feelings of safety can be included under Self Perception of Health and Wellbeing.

Patient Experience

NDSIRG agrees with nuancing this further and that it should be framed in accordance with the UNCRPD.

Use of Information Technology

This topic covers access to, and use of computers and the Internet – both at home and outside the home. It also covers whether the internet was used for access to government services or for private purposes.

There is an increasing focus on provision of information and services to people with disability via the Internet. Many households still do not have access to a computer or Internet, necessitating the need to send documentation or information by mail. NDSIRG considers it important to **retain** this topic but nuance to ask if technology is used to obtain information and agrees that further questions would be useful as this would enable comparison of people with disability with others to look at digital exclusion.

Attendance at Supervised Activity Programs

NDSIRG agrees that this information can be obtained from other sources, however, as the language is unclear, this topic could in fact relate to a prison or child access visit.

NDSIRG would appreciate the ABS clarifying what this refers to – does it relate to someone that needs support throughout a specific activity or group activity? In addition can the ABS clarify what is this data collected for and what is it a measure of.

Experience of Homelessness

NDSIRG considers it important to **retain** this topic to ensure there is data that indicates whether disability impacts on homelessness. It is important for this information to be collected and available somewhere (SDAC or GSS) so the information on disability and homelessness in one data set.

It is not clear from the description provided if homelessness services, rooming houses, boarding houses, domestic violence refuges etc. are included. There is a lot of anecdotal and research evidence of people with mental illness, ABI, intellectual disability who are experiencing homelessness.

Participation in Education

NDSIRG agrees that this topic should be expanded. It is unclear whether the educational attendance includes a measure of whether it is full time/part time attendance? Many families report that their child only attends school on a part time basis? Is it possible to obtain information on how education is being accessed i.e. home schooling, school based, distance education? There doesn't appear to be data currently available on this.

In addition NDSIRG has some concerns around the assumptions with statements such as 'cannot access education because of their disability'. These statements are contrary to the social model of disability.

Will there be questions such as – Can you not access education because of discrimination, low expectation, inadequate resourcing, community attitudes of low expectations, ongoing bullying?

NDSIRG also suggest that the ABS discuss with DEEWR the national data collection on students with disability, including the need for identification of what data each collection obtains e.g. do we want two measures of same areas to validate or do you want each process to collect different statistics on education.

Participation in Employment

NDSIRG considers it important to expand this topic to include barriers to employment such as employer attitudes.

CARERS

Characteristics of carer

Only people over the age of 15 years are included as carers in the SDAC. This means that children (often of a single parent) who are carers do not get to respond.

NDSIRG would like to see the age limit lowered (probably to 10 or at least 12 years of age) in the 2015 SDAC as this would provide better data on young carers.

In many SDAC questions where the person is asked to nominate 'what relation are/is to....' there is no option for a sibling to be the response. The closest is Q9 - Other male relative and Q10 - Other female relative. As siblings often take on the role of carer (both primary and secondary) it would be useful to include that as an option.

CONCLUSION

NDSIRG acknowledges the range of issues covered by the proposed 2015 SDAC is satisfactory. However, NDSIRG has some concerns in relation to the ABS' proposal to either remove or amend certain topics under the 2015 SDAC, which have been addressed.