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Response to questions taken on notice by the AIHW at the hearing into the Inquiry into Regional and Remote Indigenous Communities by the Australian Senate Select Committee on Regional and Remote Indigenous Communities

Question 1

I would like to draw your attention to the national peri-natal data collection. I am looking at table five, which is listed on page 13 of your submission, on live born, low birth-weight babies. I note that the data is 2003 to 2005. Do you have any updated data that you could provide the committee on that particular area?

Answer

The most recently published data is for 2006. Overall, the proportion of low birth weight babies born to Indigenous mothers in 2006 was 12.4% compared with 6.2% for babies born to non-Indigenous mothers. Between the two periods 2005 and 2006 there has been a decline in the proportion of low birthweight babies of Indigenous mothers (13.2% in 2005 to 12.4% in 2006). Given the small numbers involved and the variability year to year it is not possible to state that there has been a real decline in the proportion of low birthweight babies born to Indigenous mothers.

Question 2

You raise the issue of smoking in your submission. In some states, and I think nationally too now, there are some efforts around smoking in Aboriginal communities. Are you starting to notice any impact from those programs?

After some discussion, Dr Allbon took the question on smoking on notice to provide latest data.

Answer

The most recent published data on smoking during pregnancy by Indigenous status is for 2006. While there seems to be 1% point decrease between 2005 and 2006 data in the proportion of Indigenous mothers who smoked during pregnancy (52.1% in 2006 compared with 53.1% in 2005), in the absence of longer-term trend data, it is not possible to say that there has been a real decline in smoking in pregnancy. These data are available in AIHW report *Australia's mothers and babies 2006.*

Question 3

As we have moved around especially in the Kimberly area and Fitzroy Crossing, the foetal alcohol syndrome was drawn to our attention. How can we find any further data on that as it is spread across Australia rather than in one specific area? Are you looking at that under this peri-natal dataset?

Answer

Data on low birthweight babies born to Indigenous and non-Indigenous mothers is collected through the National Perinatal Minimum Data Set (NPNMDS) and this data is available annually. Work is underway to include data on alcohol use during pregnancy in the National Perinatal Minimum Dataset. It will take some time for this new data item to be reported on in the National Minimum Dataset as there is a rigorous process to be followed before new items can be reported on nationally.

Once this data are available it will be possible to explore the relationship between alcohol use in pregnancy and low birthweight babies for Indigenous mothers on a national basis.

Feotal Alcohol Syndrome (FAS) is difficult to diagnose at birth. Diagnosis of FAS requires medical confirmation based on a set of clinical guidelines. A national study in Australia found that the median age at diagnosis of FAS was 3.3 years with only 6.5% being diagnosed at birth, and 63% being diagnosed at less than 5 years of age (see attachment 1 for more details).

Other data sources that can be used to obtain information on FAS include hospitalisations and mortality. Using information from these datasets is likely to underestimate FAS because of difficulties in diagnosis. However, analysis of hospital and mortality data shows that there were 12 hospitalisations for FAS for Indigenous persons nationally when data for 5 years (2002–03 to 2006–07) were combined. And over the period 2002 and 2006, there was one death from FAS for a non-Indigenous person.

Why is it difficult to diagnose FAS

In Australia currently there is only one national study that provides information on the prevalence of FAS. This study identified a number of problems that affect the completeness of data on FAS. These include:

- Difficulty in diagnosing FAS early
- Currently FAS is perceived as a rare condition partly due to under-identification
- Insufficient information available on medical records to define FAS cases. This makes estimation of incident cases difficult
- Under reporting of cases due to lack of recognition and referral by non-specialists
- Lack of clinicians trained to identify FAS
- Lack of access to clinical services in rural and remote areas makes it difficult to assess the prevalence of FAS

Question 4

The questions were

"Is there any evidence that you record on the number of Indigenous carers in these communities, and specifically looking after the elderly population and people with disabilities?" and

"We have just had evidence that most of the Indigenous carers are over the age of 50 and they are on disability pensions themselves when they get to 50. I wonder if that perhaps blurs the data of these people that are included on disability pensions; therefore they would not be recognised as carers. Very few of them can actually access a carer's payment or be recognised as carers. Do you have any way that you can work through that one?"

Existing data sources

There are a number of data sources about carers, all of which have limitations which affect our ability to identify all carers who may need support and assistance, and more particularly the numbers of older Indigenous carers in regional and remote communities.

ABS data sources

The ABS Survey of Disability, Ageing and Carers (SDAC) is regarded by the ABS and AIHW as the best source of data about carer status and disability status. This survey in 2003 identified 2.5 million carers providing unpaid assistance to someone with a disability and a much smaller number of 'primary' carers (the main provider of assistance to a person who needed ongoing help with self-care, mobility or communication) – 474,600 confirmed primary carers according to the SDAC definition of 'primary carer'. But this survey does not collect data about Indigenous status so it is not possible to identify Indigenous carers. In addition, it is a sample survey designed to provide national and jurisdiction level estimates for the total population. It is not designed to provide estimates for Indigenous people, their communities in remote areas or for remote areas in total.

Similarly the ABS 2006 General Social Survey which also includes questions on carer status and disability status does not collect data about Indigenous status and is also designed to provide national and jurisdiction level estimates.

The ABS 2006 Census

The ABS collected information in the 2006 Census on people who provided unpaid care for a person with a disability, a long-term illness or problems related to old age. This can be disaggregated for small areas provided there is a sufficient population size. However, there is evidence that both need for assistance with core activities (the severe end of the disability spectrum) and caring were under-reported or not stated in the 2006 Census, especially by Aboriginal and Torres Strait Islander people.

While the majority (62 per cent) of non-Indigenous carers in the Australian population are aged 45 or over, the profile of Indigenous carers is younger, with only 33 per cent aged 45 or over. The younger age-profile of Indigenous carers persists even after adjusting for differences in the age structures of the two populations. The younger age-profile of Indigenous carers has been attributed to having children younger and to the onset of chronic disease and disability at a younger age (see ABS & AIHW 2008 p. 69).

The 2006 Census collected information on both provision of unpaid care for a person with a disability, a long-term illness or problems related to old age and need assistance with core activities. It is therefore possible to report on the number and characteristics of Indigenous people meeting both criteria, although the overall number is quite small (2,100) and subject to the limitations noted above. This information has been published (see ABS & AIHW 2008 p.73).

The questions used to ascertain disability and carer status used in the relevant ABS surveys and the census do not depend on whether or not a person is in receipt of a particular benefit type.

Centrelink payment data

Carers may receive income support such as Carer Payment and/or other financial assistance such as Carer Allowance from the Australian Government.

- Carer Payment is an income support payment for people whose caring responsibilities prevent them from undertaking substantial paid employment. Of the 130,657 Carer Payment recipients in June 2008, 3.7% (4,812) identified as Indigenous.
- Carer Allowance is an income supplement available to people who provide daily care and attention at home to a person with disability or a severe medical condition. Carer Allowance is not taxable or income and assets tested. It can be paid in addition to a social security income support payment, such as Age Pension or Disability Support Pension.

Therefore, Carer Allowance data from Centrelink will include carers who receive, for example, Disability Support Pension or Age Pension, but who also receive Carer Allowance. Of the 422,905 Carer Allowance recipients in June 2008, 2.3% (9,561) identified as Indigenous. However, Carer Allowance data may under-represent the number of Indigenous carers, for several reasons.

- Firstly, it is voluntary, not compulsory, for Indigenous people to identify as such when claiming Centrelink payments.
- Secondly, there are eligibility criteria which test the level of care that is required and provided, that need to be met in order to be eligible for Carer Allowance. Carers who receive Carer Allowance must provide a significant level of care, which would be comparable (but not equivalent) to the level of care provided by a primary carer (the eligibility criteria are not the same as the definitions used in the SDAC). Therefore, at best, Carer Allowance approximates primary carers only. In situations where the criteria are not met, the carer would not be eligible for Carer Allowance.
- Thirdly, the Report of the Carer Payment (child) Review Taskforce identified issues regarding equitable access to Carer Payment for Indigenous carers. Some of these may also apply to Carer Allowance. The Report states that there are complex kinship roles and relationships that may impact on caring roles and responsibilities. People may not identify themselves as carers. Further, the Report states that the kinship or shared model of care has many benefits for the individual and community, but this model of care is not well supported by the current system.
- Finally, in focus groups, issues for Indigenous carers such as difficulty understanding the payments and the forms were identified.

The Department of Families, Housing, Community Services and Indigenous Affairs has funded a project under its Social Policy Research Services Agreements, to explore what is known, what further information is needed, and how can further information best be obtained, about Indigenous carers.

Conclusion

Though it is likely to underestimate the number of Indigenous carers, the best data source available about Indigenous carers, especially those in regional and remote communities, is the ABS Census.

Receipt of Carer Allowance, which can be received in addition to income support payments such as the Disability Support Pension, may provide some indication of the levels of care being provided in these communities, however the actual take up of this payment by Indigenous carers may understate caring responsibilities.

Clarification of information provided in the AIHW submission and during question

In relation to being able to report data on young people in the juvenile justice system by region or remoteness, the AIHW submission and answer to questions at the hearing were inadvertently incorrect. Both gave the impression that the necessary information to construct data by geographic areas was not available using this dataset.

AIHW would like to clarify that the juvenile justice data collection held at the Institute collects information on the postcode of last place of residence of the juvenile offenders. However, this information is considered unreliable by the data providers and therefore it is not possible to derive region or remoteness groupings using the available information at present.

AIHW will continue to work with the Juvenile Justice Data Administrators to improve the quality of geographic information collected.

Attachment 1: Fetal Alcohol Syndrome

Introduction

Exposure to alcohol *in utero* can cause a range of disorders, known as fetal alcohol spectrum disorders (FASD). One of the most severe outcomes of drinking alcohol during pregnancy is fetal alcohol syndrome (FAS). FAS leads to lifelong physical and mental disabilities in affected babies. The key features of FAS are abnormal facial features, growth deficiencies, and central nervous system (CNS) problems. FAS is a chronic condition which affects every aspect of an individual's life and the lives of his or her family. For example, people with FAS can experience problems with learning, memory, attention span, communication, vision, hearing, or a combination of these. These often lead to difficulties in school and problems getting along with others (Bertrand et. al 2005).

FAS is preventable by abstaining from alcohol use while pregnant. The draft alcohol guidelines for Australia released for comment in 2007 states that 'not drinking is the safest option' for pregnant women and women planning pregnancy (Elliot & Bower 2008).

Diagnosis of FAS at birth is difficult. In a national study in Australia it was found that the median age at diagnosis of FAS was 3.3 years with only 6.5% being diagnosed at birth and 63% were diagnosed at less than 5 years of age (Elliott and Bower 2008; Elliott et al. 2008).

FAS in Australia

There are a few data sources providing information on FAS in Australia where the overall birth prevalence of FAS ranges from 0.06 to 0.68 per 1,000 live births. The only source of national data on FAS currently available in Australia is the prospective national surveillance study conducted between 2001 and 2004 by the Australian Paediatric Surveillance Unit. The results from the study showed that the reported annual FAS rate for children aged 15 years or less at the time of diagnosis was 0.58 per 100,000 children and for children under the age of 5 years at the time of diagnosis the rate was 1.14 per 100;000 children. Birth prevalence of FAS was 0.06 per 1,000 live births. Note that these results were based on a small number of cases (92 cases nationally) (Elliot et al. 2008).

The above study also indicated that there was a significant increase in the number of children with FAS reported each year from 2001 to 2004.

While there have been no previous national studies, FAS rates have been estimated in other small scale studies. Using the Western Australian Births Defects Register and the Rural Paediatric Services Database, the birth prevalence of FAS has been estimated to be 0.18 per 1,000 live births in Western Australia but this is considered an underestimate (Elliott, Cronin & Zurynski 2004; Elliot et al. 2008). In a 10-year retrospective review of medical records in the Top End Northern Territory, there were 17 children with definite FAS and a further 26 with partial FAS. The overall birth prevalence of FAS in this study ranged from 0.68 (based on definite cases only) to 1.87 (including both definite and partial cases of FAS) per 1,000 live births (Harris & Bucens 2003).

Overseas studies have shown that in USA, the birth prevalence of FAS was 0.5 to 2.0 per 1,000 live births and in Europe the rate was similar to that in Australia. However, there are some overseas communities with much higher rates of FAS. For example, the birth prevalence of FAS in Cape Province of South Africa was 46 per 1,000 live births. The low rate of FAS in Australia is likely to be due to under diagnosis, lack of knowledge about FAS and under-recognition of the condition by health professionals (Peadon et. al 2007).

FAS among Indigenous Australians and other Indigenous people

Data from the prospective national surveillance study conducted by the Australian Paediatric Surveillance unit showed that the reported rate of FAS among Indigenous children aged 15 years or less at diagnosis was 8.11 per 100,000 while the corresponding rate among non-Indigenous children was 0.18 per 100,000. The same study found that rate of FAS among Indigenous children who were under 5 years of age at the time of diagnosis was 14.6 per 100,000. The rate for non-Indigenous children who were aged less than 5 years at the time of diagnosis was 0.37 per 100,000.

A Western Australian study found a birth prevalence of 2.76 FAS cases per 1,000 Indigenous live births and the comparative rate for non-Indigenous babies was 0.02 FAS cases per 1,000 live births. Nearly all FAS cases found in the Top End study mentioned in the previous section were for Indigenous children. The prevalence of FAS with a confirmed diagnosis among Indigenous children was estimated to be 1.87 per 1,000 live births. If FAS cases that satisfied the partial diagnosis criteria were included, the prevalence would have been 4.7 per 1,000 live births for Indigenous children.

Studies of native Americans in USA have shown that FAS had a birth prevalence of 9.8 per 1,000 live births, a much higher rate than that found among Australian Indigenous population. This is likely to be due to under-estimation of the true prevalence of FAS in Australia (Peadon et. al 2007).

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