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Dear Mr Crawshaw

Thank you for the invitation to provide a written submission to the Senate Community Affairs Reference Committee *Inquiry into grandparents who take primary responsibility for raising their grandchildren*. The Australian Medical Association (AMA) welcomes the opportunity to provide the Senate Committee with comments on aspects relating to the needs of grandparent carers. It is important to note that these needs cannot be considered in isolation and significant consideration must also be given to the needs, including medical and other care needs, of the children who are cared for by their grandparents.

Setting the scene

In 2013 the Social Policy Research Centre at the University of New South Wales published the report *Grandparents raising grandchildren: Towards recognition, respect and reward*. The Report draws on multiple sources of data, including a comprehensive literature review, analysis of statistics from the Australian Bureau of Statistics (including Census data), a survey of grandparent carers, interviews with Aboriginal and Torres Strait Islander grandparents and focus groups and interviews with service providers and policy makers. Given the depth of this Report it is worth noting some of its findings at the outset of this submission:

- **It is extremely difficult to quantify the exact number of children who are cared for primarily by their grandparents.**

This is because a significant number of arrangements are informal and are not identified by current data and statistical collections. Despite this, there is a strong consensus that the number of children being cared for primarily by their grandparents in Australia is growing;

- **Currently there is no national data collection that identifies the reasons why children may end up being cared for by their grandparents.**

Historically, the reasons that grandparents assumed care for their grandchildren included parental death, illness and disability. While these reasons remain, more recent literature identifies abuse (including substance and alcohol abuse by parents), risk of child abuse and neglect, parental incarceration, parental mental health problems and disability of grandchildren as reasons that can contribute to a transition

in primary care arrangements for children. Literature from Australia and overseas identifies parental substance abuse as a possible driver for much of the growth in 'kinship' (not limited to grandparents) care in recent years.

- **Care arrangements may be formal or informal.**

There are three main routes / process ways by which grandparents can assume care for their grandchildren

- Via state and territory child protection services which make statutory out-of-home kinship care placements;
- Via Parenting Orders, which can be made by the Family Court of Australia or the Federal Magistrates Court;
- Via an informal arrangement whereby the grandparent assumes care.

Grandparents with these informal arrangements have differential access to supports, services, payments and other benefits. Informal arrangements may be temporary or permanent.

- **The age of grandparents assuming primary care for their grandchildren varies.**

Surveys have identified some primary caring grandparents to be in their 30's while others are in their 80s and even 90s. The majority tend to be in their 50s and 60s.

This means that grandparent carers may be experiencing age-related health declines.

- **Grandparent headed families are significantly more likely to experience financial disadvantage.**

This may be because grandparents have limited or set incomes, they may have ceased work, work part time or are unable to work. Caring for children costs money and in many instances grandparents may not have factored in the significant expense of raising one or more of their grandchildren. This unforeseen expense can result in the need to sell assets, such as the family home as well as drawing on investments and retirement savings, including superannuation. Grandparent carers may not always be aware of the financial support that they are eligible for. Focus group feedback from service providers identified a strong theme that there was a reluctance among some grandparents to access government payments such as Family Tax Benefit or other parenting payments because they feared intimidation or violence from the middle generation if they ceased to receive the payment as a consequence.

- **Health and wellbeing presented as a significant problem for grandparent headed families.**

More than 50 per cent of grandparents reported that their grandchildren had a physical health problem, and 80 per cent reported emotional and behavioural problems, resulting in a significant number of children experiencing both physical and mental health problems. Types of problems most frequently reported by grandparents include Attention Deficient Hyperactivity Disorder, anger, anxiety, depression, Asperger's Syndrome, asthma, attachment disorder, bedwetting and drug and alcohol misuse in older children.

- **Children who have experienced abuse and neglect can experience behavioural and developmental problems which require specialist intervention.**

Children who have experienced abuse and neglect often have complex health and development needs which require specialist support from a range of professionals. This support must be timely and well-coordinated.

- **Gaining access to specialist health and development services was identified as a significant problem by grandparent carers.**
Grandparents reported that accessing the range of health and other services that their grandchildren had been referred on to was often overwhelming and in some instances problematic. Financial pressures along with geographic location (with more grandparent carers living in rural and regional areas), and their own health needs may contribute.
- **Problems of access are further compounded when grandparents are unable to establish their authority as the primary carer for the child with health care providers.**
This is largely due to instances of informal care arrangements, and may impact on access to Medicare cards and the provision of consent for medical procedures.
- **The health and wellbeing of the primary caring grandparents is an issue of significant concern.**
Survey data indicates around half of grandparent carers have a long term illness or disability, and over half (62 per cent) reported that their health had declined due to raising their grandchildren. The reported physical conditions include high blood pressure, arthritis, diabetes, asthma back problems and cancer. Grandparents are also likely to experience a decline in their mental health and wellbeing as a result of care giving. In a US study 30 per cent of grandparents who assumed care experienced psychological distress that required clinical services. Some studies have shown that grandparents may overlook or play down their own health issues because they are fearful of authorities removing the children from their care.
- **Despite the challenges they face, many grandparents are steadfastly committed to providing care for their grandchildren.**
Children who are placed in the care of their grandparents often do much better than if they were to be placed in other settings, and many grandparents report that caring for their children is fulfilling and satisfying.
- **Aboriginal and Torres Strait Islander children are over represented in ‘out of home’ care.**
Estimates taken from the 2006 census indicate that Aboriginal and Torres Strait Islander children represent one third (or 32 per cent) of children living with grandparents. However ‘kinship’ care, including primary care provided by grandparents may not have the same cultural significance because family members have traditionally been involved in raising younger generations. This does not negate the need for support. Aboriginal and Torres Strait Islander grandparents report a need for financial and other support, including support to access appropriate health care for the children, as well as for themselves. This support must be culturally sensitive and targeted specifically to suit their needs.

Significant issues

- Many grandparent headed families face significant financial pressure. This was the greatest cause for concern among grandparent carers. Financial difficulty may be exacerbated by fears around accessing relevant government support payments.

Decreased financial resources may lead to reduced access to health care and related treatment for both grandchildren and grandparents.

- In addition to financial barriers, other barriers may reduce access to care and support, including, informal care arrangements, geographic location, services already being overburdened, lack of awareness about services and the grandparents own health problems.
- Health and wellbeing is a significant issue for many children who are cared for primarily by their grandparent. Health concerns may be complex, requiring an increased amount of medical oversight, as well as a need to access allied health and other relevant professionals.
- Children in informal care arrangements may lack of access to a Medicare card / number, and it may be difficult for grandparents to provide consent to medical treatment under these circumstances.
- There is little in the way of practical advice and support for grandparents, and the treating medical practitioners (and other health professionals) about how to approach these situations when they arise.
- Older children who are in the care of their grandparents may be at higher risk of engaging in alcohol and drug abuse.
- For various reasons grandparents report that their health declines as a result of taking on responsibility as primary carer for their grandchildren. Increasing access to health and other support services for children who are cared for by their grandparents should reduce some of the stress that many grandparent carers face.
- In some instances, sometimes due to their own declining health and wellbeing, grandparents may have to consider relinquishing care for their grandchildren.
- Aboriginal and Torres Strait Islander children may be more likely to be raised by their grandparent or other family members. Targeted, culturally sensitive support services must be available to these families.

AMA Recommendations

1. Improved data collection.

Due to the lack of reliable data around the number of children who are being primarily cared for by their grandparent/s, it is important that efforts are made to enhance the collection of reliable and up to date on these children and their grandparents. This data will help inform governments and others about the current levels of need, as well as assisting with the development of policies and funding of services for this group.

2. Consideration of increased financial support in order to cover essential services such as health care

There are a number of factors which contribute to the increased likelihood that grandparent headed families will face significant financial pressures. These pressures can make the situation for the family more precarious and may contribute to reduced access to essential services, including health and welfare services. Health status is also linked to many other areas such as housing and education which may also be negatively impacted by increased financial disadvantage.

In relation to healthcare specifically, reduced financial resources may mean that grandparents are put in a position of needing to prioritise the various health care and other needs of the child (including medications and treatments). Given their lack of health expertise, this is not ideal. It may also mean that grandparents place the health needs of the children they care for above their own needs, which may contribute to declines in their own health and wellbeing, and ultimately reducing their capacity to care for the children.

There is fairly strong evidence that many grandparents are not always aware of government and other (i.e. charity) support payments that they may be eligible for. Efforts must be made to increase awareness and ease of access to this support for grandparent carers.

There is also evidence that grandparents may be reluctant to access government payments if it will be perceived as detrimental to their own children (the parent) as a result. Focus groups with service providers highlighted threats of violence and intimidation as being a significant issue for many grandparent carers seeking access to government payments. While this may not be an easy situation to resolve, concerted efforts must be made to ensure the safety of children and grandparents in those instances where they are likely to encounter such threats and violence.

Many grandparents assume primary care for their grandchildren under informal arrangements, resulting in reduced access to financial and other supports. Despite this, the children may still have significant health needs. Consideration should be given to providing financial support in instances of informal care arrangements where there is a high level of need and families are unable to afford essential services, including health care.

3. Concerted efforts to improve access to health care for children who are cared for primarily by their grandparent

The literature reveals that children who are primarily cared for by their grandparents are likely to have increased health and welfare needs. The health and welfare needs of the child are paramount, and every effort should be made by governments and professionals to ensure that these children have timely access to the relevant services. Early intervention and other supports may reduce the need for support in the future.

When both a child and their grandparent have significant health needs, and there is an established financial difficulty, case management type support may be required to ensure that

both the child and grandparent receive the medical and other care they require. In these instances the case managers should liaise closely with the child's treating medical professional as well as allied health and other professionals, in order to ensure the best outcomes for the children and their grandparents.

It may also be appropriate to consider increased investment in targeted interventions for established health risks, such as those aimed at identifying and supporting older children who may be at increased risk of alcohol and drug abuse.

4. Support for the grandparents

It is important that grandparents who take on the responsibility of becoming a primary carer for their grandchildren are well supported. The literature identifies this is not always the case. It is critical that there is more widely circulated, targeted information available to grandparent carers. This information must be available from a range of sources and also made available in a range of languages.

There should also be some consideration given to the feasibility of providing grandparents who are primary carers for their grandchildren, with access to the same types of supports that are available to foster parents. In addition, a stocktake of services available to both grandparents and foster parents in each State and Territory should be undertaken in order to identify any significant inconsistencies across the jurisdictions, as well as gaps in services, that aim to support children whose parents are not their primary care givers.

Another avenue worth further investigation is the establishment of a 24 hour telephone support line that is available for all grandparents who find themselves in a situation of providing primary or significant amounts of care for their grandchildren, whether it be in a formal or informal care arrangement. The support line must be able to provide grandparents with up to date advice on a wide range of issues, including health and welfare needs.

It is also important to recognise the need for appropriate support in those instances where a grandparent finds themselves unable to continue to care for their grandchildren (due to health and other reasons). This support must focus on reducing the stress and trauma associated with the transition in care.

5. Education and other pertinent resources for relevant professionals, including medical practitioners

Information packages tailored to meet the needs of general practitioners and other medical specialists should be compiled and dispatched in order to provide information about the types of health problems that are prevalent among children, and their grandparents, in grandparent headed families. This information should also provide specific guidance on how to access Medicare numbers and appropriate consent for medical procedures when the child is in an informal care arrangement. It is also important that the information includes reference to the appropriate contacts for those instances when the treating medical practitioner believes that

financial and other difficulties are likely to prevent a child from accessing the appropriate medical care.

6. Grandparents who provide significant amounts of care, but are not primary carers

While the issue does not fall specifically within the Terms of Reference for the current Inquiry, it is worth noting that grandparents are increasingly relied on to provide care for children while their parents work. This type of care can range from a few hours to full time care for five days per week. The arrangements are often fairly informal, but in some instances it may be seen as unrewarded expectation for which the grandparents can incur additional costs and face restrictions in their own activities. Many grandparents provide this type of care happily and willingly, but the extent of grandparent childcare and the subsequent effects of both the grandparents and grandchildren warrants further research.

In summary, the AMA recognises that children being cared for primarily by their grandparents may have increased need for support. In many, if not all cases, the grandparent or grandparents may have additional needs as well. The AMA supports efforts to identify and reduce barriers to accessing essential services, such as health care, for this group. The AMA also recommends efforts to increase awareness and education about the specific needs of this groups among the various professionals, including medical practitioners, who are likely to encounter children and grandparents in both formal and informal caring situations.

I would like to thank the Senate Community Affairs References Committee for undertaking the *Inquiry into grandparents who take primary responsibility for raising their grandchildren*. Should any questions arise in relation to the comments contained in this submission, please contact Dr Maurice Rickard, Manager of the AMA's Public Health Section on 02 6270 5400 or mrickard@ama.com.au

Sincerely



Steve Hambleton
President