

**Alliance for Forgotten Australians (AFA) submission to Productivity
Commission Inquiry, *Caring for Older Australians***

14 December 2010

Introduction

Among the Terms of Reference of the Inquiry are several aspects that relate directly to adult survivors of childhood institutional or other out-of-home care (generally known as Forgotten Australians or Care Leavers), particularly:

- Examine the social, clinical and institutional aspects of Aged Care in Australia (including services currently delivered under the Home and Community Care program for older people) that:
 - ensure access (in terms of availability and affordability) to an appropriate standard of aged care for all older people in need, with particular attention given to the means of achieving this in specific needs groups including people living in rural and remote locations, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, and veterans;
 - : The Commission is specifically requested to examine how well the mainstream service system is meeting the needs of specific needs groups.
 - support independence, social participation and social inclusion, including examination of policy, services and infrastructure that support older people remaining in their own homes for longer, participating in the community, and which reduce pressure on the aged care system;
 - support independence, social participation and social inclusion, including examination of policy, services and infrastructure that support older people remaining in their own homes for longer, participating in the community, and which reduce pressure on the aged care system;
- Systematically examine the future workforce requirements of the aged care sector, taking into account factors influencing both the supply of and demand for the aged care workforce, and develop options to ensure that the sector has access to a sufficient and appropriately trained workforce.

As a group, survivors of institutional care remain fairly isolated, but one thing that unites them is their fear of re-institutionalisation.

In this submission, we seek to provide an overview of the social, health and institutional issues for Forgotten Australians; to emphasise the need for priority access and targeted places in community settings for institutional care survivors; to stress the importance of inclusion, participation and decision making for marginalised groups; to stress the complexity of navigating the current system and the impact this has on people who have

experienced stigma and marginalisation; to urge that attention be given to the needs of poor and homeless people; and to stress the importance of a skilled and knowledgeable workforce in dealing with this population of traumatised adults.

Background

Forgotten Australians

The people who identify as Forgotten Australians are survivors of the roughly 500,000 children who found themselves in orphanages or Homes in the 20th century. Some were in State care, because the State considered their parents unfit or the children 'at risk'; some had parents who were dead, in prison, missing or otherwise unable to care for them; some were given up by their parent/s because the parent/s could not provide for them. Sometimes these parents had to work and to use the Home as a form of child care. If they could, they paid maintenance to those running the Home. Often, the parent/s had returned from war, physically or mentally damaged.

Some of these children were Aboriginal; some were child migrants from Britain or Malta; the vast majority were non-Indigenous Australians. Large numbers of these children experienced serious and often criminal physical, sexual and emotional abuse, neglect and assault.

The Australian Senate Community Affairs References Committee conducted an Inquiry into the experiences of these children and the outcomes for them as adults. The Inquiry allowed many people who had been children in the Australian institutional care system to tell their stories – often for the first time. The report, *Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children (2004)*, revealed a history of neglect and cruelty, of abandonment and exploitation.¹

For the adults, now generally aged from around 50 up (although some are younger), the long term impacts include: poor health; low education outcomes, including low literacy levels; a lack of social skills; a lack of trust and security; inability to form and maintain loving relationships; inability to parent effectively; a history of depression or anxiety, including symptoms of Post Traumatic Stress Disorder (PTSD); and risk-taking behaviours such as substance abuse.

The Alliance for Forgotten Australians (AFA)

The Australian Government response to the Senate Report included funding for a national conference in 2006 that brought together Forgotten Australians and their support organisations, past providers of institutional care, community organisations and service delivery agencies. At that conference, the Forgotten Australians resolved to form a national peak body, made up of organisations and active individuals working with Forgotten

¹ See also the other reports in the trilogy, *Bringing them Home: Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families*, Human Rights and Equal Opportunity Commission, April 1997; and *Lost Innocents: Righting the Record – Report on child migration*, Senate Community Affairs References Committee, 30 August 2001. See also a follow-up Senate report, *Lost Innocents and Forgotten Australians Revisited*, June 2009.

Australians in every State and Territory. Funding has continued through the Department of Families, Housing, Community Services and Indigenous Affairs.

AFA aims to promote the interests of Forgotten Australians (including child migrants and many Indigenous Australians) through advocacy and to educate the community through awareness-raising projects. We have distributed over 100,000 copies of our booklet, *Forgotten Australians: supporting survivors of childhood institutional care in Australia*. (A copy of the booklet will be posted with the hard copy of this submission.) Ms Caroline Carroll is our Chair. Auspicing and project support is provided by Families Australia.

AFA is not a support organisation but a national collaborative peak body. Our primary objectives are to promote the needs of Forgotten Australians through awareness-raising and advocacy and to improve the lives of these survivors.

Comments

AFA welcomes this opportunity to provide input to the Productivity Commission's Inquiry. This submission focuses on the specific needs of people who have experienced institutional care and who bear the scars of powerlessness and ill-treatment.

As a large and diverse group of often quite isolated individuals, Forgotten Australians often have difficulty managing their day-to-day lives. Their very survival is a sign of their innate, and learned, strengths. Their day-to-day interactions with organisations tend to be strongly influenced by their fear of abuse of power, their own sense of inadequacy and their anger and hurt.

The 2004 Senate report, *Forgotten Australians*, made two specific recommendations about aged care needs:

Recommendation 26

That the Department of Health and Ageing fund a pilot program under the Aged Care Innovative Pool to test innovative models of aged care services focussing on the specific needs of care leavers.

Recommendation 27

That the Home and Community Care program recognise the particular needs of care leavers; and that information about the program be widely disseminated to care leaver support and advocacy groups in all States.

Originally, the Howard Government took the view that Forgotten Australians can access health care and other programs which are available to all Australians. This attitude did not address the multiplicity of issues confronting Forgotten Australians and their need for holistic, targeted and understanding assessment and referral for all their issues. In AFA's view, health issues must be treated in the context of the causes of them, and treating professionals must be aware of the past abuse and the consequent level of mistrust by many Forgotten Australians of doctors and other medical staff.

There is a need for multiple entry points within all relevant services for Forgotten Australians, directing them to a range of specific services. An holistic, case management

approach will be most effective. Treating one issue while ignoring others, in a service-based approach, is of limited value for people who face multiple and interactive barriers to social and economic participation.

Aged care service provision will be a growing problem for Forgotten Australians. Having been helpless and abused in institutions as children, many of them fear that their own growing helplessness as adults will necessitate institutional placements for them. The tendency of abuse survivors to have difficulty forming and maintaining relationships also means that, in many cases, family will not be available to assist with care. Alternative care models need to be explored urgently for this group. Education of aged care service providers is imperative.

To the best of our knowledge, no progress was made on the Australian Government's expressed willingness to test innovative models of aged care service for this group under the Aged Care Innovative Pool. No agency appears to have taken up this suggestion.

However, Forgotten Australians' issues have, to some extent, been recognised by the current Australian Government. On the day of the national apology to Forgotten Australians and Child Migrants, (then) Prime Minister, the Hon Kevin Rudd MP, announced commitments from the Government to a number of projects designed to assist adult survivors of childhood institutional or other out-of-home care. On aged care, the Government committed to identifying care leavers as a special needs group (done); to supporting the development and distribution of education materials for providers and carers in the aged care sector (in train); to providing appropriate and responsive care, including access to counselling and support services; to ensuring the needs of Forgotten Australians and former child migrants are reflected in the agenda of the Ministerial Conference on Ageing and the Ageing Consultative Committee; and to disseminating information about state and regional specific programs funded under the Home and Community Care Program to Forgotten Australians and former child migrants.

These initiatives have been widely welcomed. AFA has been involved in consultative mechanisms around their development and implementation.

Nonetheless, we remain concerned by the situation of many Forgotten Australians, noting that:

- People who suffered physical, sexual and/or mental abuse in institutions as helpless children are usually terrified of returning to an institution. The Senate report quoted people as saying they will kill themselves first. Institutionalisation is a genuine and terrible fear, grounded in personal experience.
- Many Forgotten Australians have never spoken of, or dealt with, their trauma. It remains hidden. When they reach the point where they experience confusion about their current reality, many will revert to the past and live that trauma – as helpless children – afresh.
- Church-run institutions would be particularly frightening for many of them.
- Many Forgotten Australians are living with poverty and social isolation. As children, their education was generally neglected, and this has combined with lifelong trauma to produce poor life outcomes.

- Many have mental illnesses, suffer from substance abuse and/or experience homelessness; some reports indicate that they are over-represented in the criminal justice system.
- Anecdotal evidence suggests that they are over-represented in the health system and that their life span is generally shorter than that of the general population, meaning that early-onset ageing is likely to cause difficulties in negotiating for appropriate levels of care.
- Family breakup is not unusual. There is often no family to provide the 'fill-in' or crisis care that enables community care to support people effectively beyond the point where independence and personal safety are compromised in the home.
- Forgotten Australians were told, as children, that no-one would believe their complaints of ill treatment. Many found this to be true. A lasting legacy is that they do not expect to be believed. This makes many of them reluctant to speak about their abuse, neglect and trauma unless a worker shows that s/he is aware of the history and understands the long term impacts. Education of workers in the Aged Care system must ensure that, from the first contact with an assessor, Forgotten Australians will be recognised and supported.

AFA is seeking:

- A policy framework, developed in consultation with Forgotten Australians and their representatives, covering research, health service provision, HACC services, ACAT assessments, tailored direct care programs, information provision, counselling, advocacy, standards, and education and training.
- Special assistance for Forgotten Australians to access purpose-built, supported, affordable, residential models of care rather than nursing home models.
- Support with voluntary transition to those models of care while they are still healthy and independent enough to be able to settle, make friends and establish themselves as part of a community.
- Ongoing funding for special programs designed to identify and assist Forgotten Australians in the aged care system.
- Counselling support for those dealing with the trauma of their past and the terror of re-institutionalisation.
- Thorough, ongoing training and support for all workers potentially dealing with Forgotten Australians.
- Forgotten Australians' issues to be on the agenda for regular discussion at the Ageing Consultative Committee.
- Funding for specific advocacy and support services for Forgotten Australians in the aged care system.
- Priority access to aged care services for Forgotten Australians. The disadvantage experienced by Forgotten Australians as a group, because of their lack of adequate health care, education and support as children, needs to be acknowledged as a Social Inclusion issue. In some ways, because the lack of understanding by children of what is happening to them results in self-blame and lifelong shame, their situation is worse than that of war survivors.
- Isolation is a big factor inhibiting recognition by service providers of Forgotten Australians' needs as a community of survivors. Government and non-government agencies should collect and recognise data pertaining to the needs and requirements of

the Forgotten Australians as a specific group; the aim would be to ensure a better response from services.

Independent living (in a non-institutional setting) is a goal for Forgotten Australians. Like most Australians, most Forgotten Australians would prefer to stay in their own homes (where they have them), with in-home services and supports provided. Recognising that this will not always be possible, for safety reasons, AFA suggests that the ideal model for aged care accommodation and support for Forgotten Australians would:

- be affordable;
- be of a supported community variety;
- incorporate genuine independence, with private living quarters;
- have lifelong access to a high level of health care;
- offer sympathetic understanding and support from a suitably skilled and well-informed workforce;
- respect the role of 'family' even if they are not blood relatives;
- include counselling options;
- offer appropriate psycho-geriatric care and skilled palliative care if needed;
- avoid the use of bureaucratic language;
- use Forgotten Australians' names rather than generic words like 'dear' – and NEVER use numbers instead of names;
- understand food dislikes that may date back to bad childhood experiences, such as having to eat spoiled or infested food and cruel punishments for not eating particular foods;
- provide emotional support which includes access to interest groups;
- offer accredited training (and professional support) for those working with Forgotten Australians accessing aged care packages;
- possibly include group housing (small or shared facilities) with individual privacy and no more than 5-6 people per dwelling;
- possibly be part of a larger model, such as a large housing complex with mixed tenancy, fully furnished units or town houses and affordable rental set as a percentage of income, full support and linked to onsite services and designed to accommodate wheelchairs and equipment (such as the Goldcare model²);
- offer Aboriginal and Torres Strait Islander aged care facilities that are culturally appropriate in urban and rural settings;
- support Aboriginal and Torres Strait Islander Forgotten Australians and members of the Stolen Generation to return to country with necessary support to do so;

² This reference is used for illustrative purposes and does not constitute an endorsement of Goldcare as a company.

- ideally, design buildings with access to indoor/outdoor living areas – open, airy, with a small yard/deck and enough room to have visitors from family and friends;
- avoid the use of fences or locked gates.

AFA notes that, generally, the mainstream aged care system is not designed around people with lifelong health, social and economic vulnerabilities. It is a mainstream service system, so making a category of people ‘special needs’ does not necessarily change the culture or provide greater access to the system. It is important for the Productivity Commission to recognise, in its review of the Aged Care system, that creating special needs categorisations for certain vulnerable groups of citizens does not resolve difficulties with access to the system or comfort within it.

A preferred model of aged care for older Forgotten Australians would look something like the integrated aged care support and accommodation options provided by Wintringham, a secular, not-for-profit welfare company that seeks primarily to support ageing, vulnerable individuals in need of affordable and safe housing. They are identified as elderly with housing **and** support needs, and the organisation works with the person to resolve those needs, including through close liaison with Aged Care Assessment (ACAT/ACAS) and aged care service providers. In this way, the organisation takes the role of non-existent family members in relation to initiating contact with the aged care system.

Wintringham's key focus is on developing understanding and relationships with people who have survived extraordinary levels of health, social and economic vulnerability; it works hard not to re-institutionalise the elderly and vulnerable and to overcome institutional and mainstream program impediments to safe housing and supports for their clientele. This is achieved by integrating specialist social housing programs with the tranche of mainstream aged care programs.

This is, we understand, a potentially costly model; but we believe older Australians who were not protected by their governments as children deserve sensitive and appropriate care that will not re-traumatise them.

AFA is happy to discuss any of these issues with Commission representatives.

Caroline Carroll
Chair

Eris Harrison
Secretariat, Families Australia