- forming intersectoral links with other relevant NGOs, such as HelpAge, Save the Children (for the cross-generational effects) and Oxfam (for the economic impact of care and poverty reduction).

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Dementia care in Latin America – country profiles from Venezuela and Argentina

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Across Latin America, fewer than 30% of older people receive old-age pensions.

Demographic ageing is proceeding especially rapidly in Latin America. Those aged 65 years and over will increase from 33.3 million (6% of the total population) in 2005 to 56.3 million (8.5%) in 2020 and 110.2 million (14.7%) in 2040. A recent review drew attention to the relatively small number of population-based studies of dementia in Latin American countries (Ferri *et al*, 2005). Estimates based on the literature suggested 1.8 million people with dementia in 2001 increasing to 4.1 million by 2020 and 9.1 million by 2040. The increase, more than a doubling of the number of people with dementia between 2000 and 2020, was the most marked for any world region. Arguably, health and social finance systems are not well placed to meet the needs of the growing numbers of frail and dependent elderly people.

Across Latin America, fewer than 30% of older people receive old-age pensions. Most countries have moved towards multi-pillar schemes based on private, defined contribution schemes, with some bolstering by more limited public benefit elements. Brazil alone has a comprehensive non-contributory scheme, paid to 5.3 million older Brazilians at a cost of 1% of gross domestic product. Women, and those many Latin Americans who have worked in the informal sector, are disadvantaged by schemes based on defined contributions. Non-contributory schemes have been shown to be highly effective at alleviating wider poverty – they are typically shared within households, reduce vulnerability and increase economic stability.

Most Latin American countries have mixed national health systems in which public sector institutions play a relatively minor role; less than one-third of the

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population is covered by mandatory social health insurance systems and private, out-of-pocket expenditure is high. A few countries, such as Mexico, have national health insurance systems in which social insurance institutions play a major role in the provision of healthcare (often in partnership with private institutions) and statutory social insurance systems cover 50% or more of the total population. Across the continent, private income pays for more than half of all healthcare. Coverage is strongly linked to income, with an estimated 70% of the region's 200 million poor lacking access to basic healthcare.

In this paper we review the health and social care services available for people with dementia in two contrasting Latin American countries, Venezuela and Argentina.

Venezuela

The Venezuelan population is 27.0 million, of whom 1.3 million (4.8%) are aged 65 years or more. Life expectancy at birth is 71.0 for men and 77.0 for women. Most older Venezuelans subsist on defined benefit pensions provided by the state – 790 000 funded by the National Institute of Social Security and 104 000 (those living in poverty) provided by the National Institute of Geriatrics and Gerontology. Those aged 60 years or more are eligible. Although coverage is high, the pensions are meagre, rarely exceeding US$35 per month. Consequently, many older Venezuelans are still reliant on their families for economic support.

In a mixed health system, public institutions have a limited role in providing care for the elderly; in particular, they lack any specialised services for dementia care. Care is therefore mainly informal and is provided by family carers, without training and support. In the Venezuelan arm of the 10/66 pilot study of care arrangements for people with dementia (10/66 Dementia Research Group, 2004), we found that 80% had used private medical services and 15% public services; 20% had a paid carer while 7–10% of carers had stopped or cut back their work in order to care. As an index of strain, half of all carers were found to have common mental disorders.

As yet, there are no estimates of the prevalence of dementia in Venezuela. This will be rectified by the 10/66 Dementia Research Group's survey recently completed in the capital, Caracas, and an ongoing longitudinal study of 3500 persons aged 55 and over in the second city, Maracaibo, in the west of the country (Maestre *et al*, 2002). Alzheimer's Disease International's recent estimate of the prevalence of dementia in Latin America (Ferri *et al*, 2005) applied to the Venezuelan population would imply 92 000 cases of dementia in 2000, rising to 464 000 by 2040. This challenge will be difficult to meet given the current lack of formal care services. There are just 28 public nursing homes in the country, supported by the National Institute of Geriatrics and Gerontology. In addition, several private nursing homes deliver care for private, fee-paying residents and some whose care is funded by the National Institute of Social Security. Neither public nor private care homes are well resourced to provide quality care for people with dementia. Care in the community is provided only by private doctors and few of these have specific training or expertise.

The Alzheimer National Foundation has been delivering support for people with dementia and their families for the past 15 years. The Foundation delivers a year-long programme, which includes courses (of 1–2 days) for families four times a year, a day care centre and psychological support for carers. It has been disseminating information and awareness about the importance of dementia as a social, family and public health issue. Scarcity of funds has necessarily limited the scope and coverage of these activities. However, the Foundation has been building links with government agencies. A trial of the 10/66 carer intervention was due to start in August. The intervention involved training local community health workers to educate and train 30 family carers identified during the population-based survey in Caracas. This project was presented to the National Institute of Geriatrics and Gerontology, which will consider it as a pilot study with potential to be rolled out nationwide.

Across the continent, private income pays for more than half of all healthcare. Coverage is strongly linked to income, with an estimated 70% of the region's 200 million poor lacking access to basic healthcare.

Argentina

Argentina has a population of 38.4 million, of whom 9.9% are aged 65 and over. Life expectancy at birth is 73.7 years (70.0 for men and 77.5 for women). Demographic ageing is already well advanced – between 1950 and 2000 the population aged over 65 years grew threefold and the population aged over 80 grew seven times faster than the general population over the same period (Arizaga, 2002). Accordingly, there are already relatively large numbers of people with dementia (315 000) but future increases will be slightly less marked than in Venezuela and other, more typical Latin American countries, but still more than doubling, to 769 000, by 2040 (Ferri *et al*, 2005).

Men retire at 65 and women at 60 years. Retirement benefits are proportional to earnings, but with a minimum income of US$140 a month. Those who have never worked receive a pension of US$80 a month at 70 years of age.

Argentina has a mixed health system: public (county and provincial hospitals) and private (provided by prepaid health organisations, unions' health services and strictly private practice). Eighty per cent of the elderly population is covered by the different private health systems, with the remainder relying on the public system.

The Instituto Nacional de Servicios Sociales para Jubilados y Pensionados (INSSJP; National Institute of Social Services for Retired and Pensioners), created in 1971, provides social and medical attention for 3.2 million retired and pensioned persons.

We found that 80% had used private medical services and 15% public services; 20% had a paid carer while 7–10% of carers had stopped or cut back their work in order to care. As an index of strain, half of all carers were found to have common mental disorders.

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There is neither a national programme for dementia nor programmes in the different health systems. The INSSJP pays for more than 15 000 mental health beds and 15 000 long-term care beds. Many people with dementia receive institutionalised care through these facilities. Specialists (neurologists, psychiatrists and geriatricians) are concentrated in the major towns and there is a lack of access to their services for far-flung rural communities (Sarasola *et al*, 2006). There are as yet very few dementia or memory centres with a multidisciplinary specialised team (three in public general hospitals, four in private hospitals in Buenos Aires and three in private hospitals in large provincial cities). Several of these have day care and memory training programmes (Sarasola *et al*, 2006).

Awareness of dementia is generally low; many general practitioners believe that memory loss or other cognitive deficits are part of normal ageing…. Consequently, specialist referral generally occurs at an advanced stage of the disease.

In Argentina, as in nearly all South American countries, the full range of auxiliary diagnostic tools is available, including laboratory tests, neuroradiology and estimation of some genetic markers. However, access can be a problem, depending upon location, type of healthcare system, costs and eligibility for reimbursement (Arizaga, 2002). ANMAT, the regulatory agency that approves the use and sale of new drugs, has approved donepezil, rivastigmine, galantamine and memantine for use in dementia. These are subject to 30–70% reimbursement, depending on the drug and the patient's healthcare system (Arizaga *et al*, 1999).

Awareness of dementia is generally low; many general practitioners believe that memory loss or other cognitive deficits are part of normal ageing (Mangone & Arizaga, 1999; Mangone *et al*, 2000). Consequently, specialist referral generally occurs at an advanced stage of the disease (Arizaga, 2002).

The Asociación de Lucha contra el Mal de Alzheimer (ALMA; Association for the Fight Against Alzheimer's Disease) was founded in 1987. The Association is very active, providing information and support, and running a day centre in Buenos Aires for patients and families.

A basic infrastructure for research is now established in Argentina. The Consortium Argentino para el Estudio de la Demencia (CAED; Argentine Consortium for Dementia Research) agreed upon the criteria for the diagnosis of dementia and Alzheimer-type dementia (CAED, 1995) and added some modifications (CAED, 1998) to the NINDS–AIREN criteria for vascular dementia (Roman *et al*, 1993). The Mini Mental State Examination (Grupo de Trabajo de Neuropsicología Clínica de la Sociedad Neurológica Argentina, 1999), the Alzheimer's Disease Assessment Scale (ADAS; Mangone *et al*, 1995) and the Boston Naming Test (Allegri, 1997) have been translated, validated and harmonised (Grupo de Trabajo de Neuropsicología Clínica de la Sociedad Neurológica Argentina, 1999).

Annual direct costs of the disease were estimated and were found to increase with cognitive deterioration, from US$3240 in mild to US$9658 in severe Alzheimer's disease, and with institutionalisation (US$3189 in community patients versus US$14 448 in institutionalised patients). Most direct costs were paid by the family (Allegri *et al*, 2006*a*). Neuropsychiatric symptoms – including delusions, hallucinations, restlessness, anxiety, euphoria, disinhibition, unusual motor behaviour, sleep disturbances and appetite alterations – are the best predictors of carer burden (Allegri *et al*, 2006*b*).

There are no population-based epidemiological studies of dementia in Argentina. Cañuelas, a rural city 60 km from Buenos Aires, is one of the centres for the 10/66 population-based study, with recruitment of 2000 persons aged 65 and over due to be completed in 2006. One previous survey in Cañuelas showed a prevalence of cognitive impairment of 23% in people 65 and older (Arizaga *et al*, 2005).

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