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## **Dementia training for health professionals - scoping study**

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## Executive Summary

This report summarises the outcomes of a scoping survey undertaken for the NSW Department of Health (NSW Health) between March 2008 and July 2008 by the Centre for Health Service Development, University of Wollongong. The project sought to inform the Department about current opportunities for dementia education and training for health professionals in NSW. This project also aimed to guide the Department in the most effective use of one-off training funds under the current NSW Dementia Action Plan 2007–2009.

The scoping survey included interviews with 27 key stakeholder groups representing health and care service providers with whom people with dementia and their carers interact during their 'dementia journey', and with patient/client and carer representatives, as well as training providers and peak organisations. In addition, a short internet search was conducted to complement this work and inform the Department of the current opportunities for dementia education and training for health professionals in NSW.

Two key messages emerged from the study as follows:

- It is clear that dementia is core business for the health system and that this needs to be reflected at the systemic as well as local level.
- The philosophy of person centred care should underpin the delivery of health and care services.

The survey revealed the importance of targeting training to those providing front-line care across acute, community and residential care settings. However, it was also noted that everyone working in the health system could benefit from dementia awareness training. The main training needs identified included: early detection of cognitive decline and impairment; screening and assessment tools; acknowledgement of carers as partners in care; distinguishing between dementia and delirium; preventing and managing challenging behaviours; techniques to improve communication; the need to adapt clinical practice; and cognitive capacity assessment.

The majority of survey respondents commented on some level of ageism and negative stereotypes within the health and care systems, at both the direct care level, as well as systemically which directly impacted on training for staff, as well as care outcomes for clients. Respondents also indicated that there needs to be formal recognition that ageing clients and people with dementia are core business, through the development of standards, and key performance indicators to underpin the Dementia Service Planning Frameworks currently being developed under the NSW Dementia Plan. It was argued that this was imperative to drive appropriate service planning and resourcing and to set the agenda for the sector more broadly.

Other findings include the fact that whilst dementia education and training is already available, not everyone who needs training receives it. In particular, there are key gaps in course content and access to training opportunities remains problematic. The main barriers to training include workforce pressures, budgetary constraints, and a lack of management support. Additional resources, such as funding for back-filling staff to attend training are required to address these barriers. Further, greater use of flexible delivery strategies such as telehealth and e-learning opportunities should be embraced. A website to promote and bring together existing training and professional development activities into one common site on the internet was also considered important. There was strong endorsement to better utilise existing expertise within the health sector through mechanisms such as in-service, case reviews and case conferencing.

Curriculum development emerged as a critical means to ensure that trainee health and care professionals have an improved understanding of how to care for a person with dementia. This

should include a recognition that older people and people with dementia are core clients of the health system.

This report contains 19 recommendations arising from the study, and which address the themes outlined above. The recommendations arising from this study are set out to address three funding levels:

- Short-term – priorities for one-off funding under the NSW Dementia Health Action Plan;
- Medium-term – opportunities for training should recurrent funding be available; and,
- Longer-term – systemic changes which could be undertaken to make dementia training more accessible and integrated within education and training programs for health professions, community care providers, and for the community in general.

This project has provided an up-to-date and independent assessment of the current training and professional development landscape in NSW. Its aim is to provide clear recommendations to the Department to move forward in this area, in terms of funding effective and high value training projects.

In considering our recommendations, we would encourage the Department to establish a steering committee of relevant stakeholders who could provide advice regarding their implementation and the development of a rigorous evaluation framework. Sufficient funds should also be provided to promote any tools or training packages that have been developed, or which will be developed arising from this project, especially for those that are internet based.



# 1 Introduction and Aims

In December 2007, the NSW Government released its third NSW Dementia Action Plan, which has the vision of

*'A better quality of life for people living with dementia, their carers and families'*

The Plan builds on the achievements and lessons learnt from two previous NSW Dementia Action Plans and links to the opportunities provided under the National Framework for Action on Dementia 2006 – 2010.

The Plan includes five key priority areas:

1. Diagnosis and Assessment, Care and Support Services that are flexible and can respond to the changing needs of people with dementia, their carers and families
2. Access and Equity to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background
3. Information and Education that is evidence-based, accurate and provided in a timely and meaningful way
4. Research into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families
5. Workforce and Training strategies that deliver skilled, high quality dementia care.

In February 2008, the Centre for Health Service Development, University of Wollongong was contracted to undertake a scoping study into dementia training for health professionals in NSW, as background to identifying strategies to address Priority 5. The purpose of the scoping study was two-fold:

1. To inform the Department of the current status of dementia specific education and training for health professionals in NSW; and
2. To guide the Department where to direct one-off training funds available under the Dementia Action Plan and where any future available investment would be most effective.

The scoping study was undertaken between March and July 2008. It comprised 27 interviews with key stakeholders representing health and service provider groups with whom people with dementia and their carers interact during their 'dementia journey', and with patient/client and carer representatives, as well as training providers and peak organisations. An internet search of resources available in Australia was also conducted as part of the project.

This report summarises the key findings of the survey and search strategies, places them within the current NSW and national policy contexts, and presents recommendations to assist the NSW Government determine future priorities to address training and workforce issues required to deliver skilled, high quality dementia care; with a particular regard for directing one-off training funds available under the current NSW Dementia Action Plan.

## 1.1 Policy context

Dementia has been on the public agenda for the last two decades or so, as the number of people living with dementia, and the impact on their carers and the broader service system have become increasingly evident. A number of major dementia-specific policy responses have been developed during this time, at both the National and State levels, which have sought to address gaps in service provision, skills and resources. At the same time, the policy landscape in which health and aged care has been delivered has fundamentally changed, with greater emphasis

placed on the role of primary and community care, prevention and early intervention, and multidisciplinary approaches to care. This has had the concomitant effect of increasing reliance on, and acknowledgement of, the role of informal carers, as well as requiring generic services to be better able to meet the needs of people with dementia and their carers.

Developments have also occurred within the field of adult education and learning, including more flexible and accessible forms of delivery such as telehealth, dedicated satellite television (Aged Care Channel), and on-line/internet educational opportunities. Concurrently, traditional methods of education (university courses, TAFE, in-service) have expanded to include dementia specific and ageing related subjects, and target different audiences (e.g. home care workers, acute hospital staff and carers).

Consequently, there has been significant investment in dementia education and training initiatives during the last two decades, targeting dementia specific services as well as generic health and care services. Despite this, dementia education and training (including content and accessibility) remains patchy within the health and community care sectors. Furthermore, as the policy landscape in which care and support services are delivered continues to evolve, education and training opportunities must adapt to meet the changing needs of the target audiences and care settings.

It is with this background, and within this context, that both the NSW Action Plan and the National Framework for Action on Dementia have placed emphasis on, and resources for, a skilled workforce to meet the needs of people with dementia and their carers.

The NSW Dementia Action Plan has identified three key strategies to address *Priority 5: Workforce and Training strategies that deliver skilled, high quality dementia care* (see Figure 1 below). This complements the work identified under *Key Priority Area 5 of the National Framework for Action on Dementia*, which has the objective of achieving 'a skilled and informed workforce for people with dementia and their carers' (see Figure 2 below).

**Figure 1 Extract from the NSW Dementia Action Plan 2007 - 2009**

**Priority Area 5: Workforce and Training strategies that deliver skilled, high quality dementia care.**

a) Support training of health workers in high quality dementia care that complements other recent training initiatives under Dementia as a National Health Priority such as the Eastern Australia Dementia Training Study Centre, based at the University of Wollongong.	NSW Health
b) Work with the Workforce Development and Leadership Branch, NSW Health to identify, promote, and address dementia related workforce issues, including workforce issues in rural and remote areas. This includes developing strategies to address medical workforce shortages around dementia diagnosis and management.	NSW Health
c) Identify dementia related workforce issues in the community care sector, and examine ways to address these issues through the HACC Learning and Development Framework and other industry development initiatives in DADHC.	DADHC

**Figure 2** Extract from the National Framework for Action on Dementia 2006 - 2010

### Key Priority Area 5: Workforce and Training

#### Outcomes

- A skilled and informed workforce is available to care for and support people with dementia, their carers and families.

#### Challenges

- A confident, informed and skilled workforce is essential for providing high quality dementia care. Attracting and retaining staff to work in dementia care is a significant challenge. Increasingly the health, community and aged care workforce needs to be able to respond to people with dementia.

- Diagnosis is essential for a person with dementia to be advised and supported to follow the most appropriate pathway, linkages and referrals for their needs. Unfortunately, in some rural and remote areas, and for some disadvantaged groups, diagnosis does not occur or is problematic given the existing limited distribution of diagnosticians.

- Review the incentives and disincentives for recruitment and retention of the dementia workforce.

#### How will we know

- Increased access to education, training and information on dementia.
- Improved recruitment and retention of the aged care workforce.

*Shaded areas indicate actions with immediate priority*

Priorities for action	Actions	Lead agency
Identify and promote linkages between the Framework and national and jurisdiction workforce strategies including National Health Workforce Strategic Framework and the National Aged Care Workforce Strategy.	Identify and promote dementia related workforce issues.	Australian Government and States and Territories
Identify incentives and barriers to participation in dementia care and the incentives and disincentives for recruitment and retention of the dementia workforce.	Undertake review.	Australian Government and States and Territories
Include dementia in training and curricula for relevant health, community care and aged care professionals.	Seek cooperation from relevant agencies/bodies.	Australian Government and States and Territories
Promote flexible strategies for professional development such as Telehealth.	Develop and implement strategies.	Australian Government and States and Territories
Promote interdisciplinary professional development.	Identify and promote opportunities and benefits.	Australian Government and States and Territories
Develop resources and promote effective training strategies to manage challenging behaviours.	Identify existing resources.	Australian Government and States and Territories
	Develop new resources.	Australian Government
	Promote existing and new resources.	Australian Government and States and Territories

These extracts show that the Australian and NSW Governments have made important policy and funding commitments to improve the quality of care for people with dementia and their carers in our community. In addition, both levels of government have implemented a number of policy and program developments within related program areas, such as the aged care, acute care, primary care, sub-acute care, and mental health care.

In NSW, these policy developments are underpinned by a broader, more encompassing plan, *A New Direction for NSW: The State Plan ('NSW State Plan')* released in 2006, and its companion document, *A New Direction for NSW. State Health Plan ('State Health Plan')*, released in 2007.

The *NSW State Plan* includes a number of elements which aim to have significant improvements for the general population, as well as for those with dementia and their carers. The key areas of *Delivering Better Services* and *Fairness and Opportunity* contain specific goals and targets which aim to improve the general health of communities, target those most vulnerable, and integrate the principle of prevention and early intervention.

The *State Health Plan* describes in more detail how it will meet the health challenges of the future, with the following seven strategic directions:

1. Make prevention everybody's business
2. Create better experiences for people using health services
3. Strengthen primary health and continuing care in the community
4. Build regional and other partnerships for health
5. Make smart choices about the costs and benefits of health services
6. Build a sustainable health workforce
7. Be ready for new risks and opportunities.

In tandem with these important policy frameworks, the *NSW Carers Action Plan 2007-2012* articulates the Government's commitment to contributing to carers achieving quality of life for themselves and the people they support, including the following five key priority areas:

- Priority Area 1: Carers are recognised, respected and valued.
- Priority Area 2: Hidden carers are identified and supported.
- Priority Area 3: Services for carers and the people they care for are improved.
- Priority Area 4: Carers are partners in care.
- Priority Area 5: Carers are supported to combine caring and work.

These NSW Government initiatives include significant investment in supporting the priority areas identified and add to those investments in program and policy developments at the national level, such as the Australian Health Ministers *National Framework for Action on Dementia 2006-2010*.

The National Framework includes a number of highly relevant initiatives, including the establishment of a series of four Dementia Training Studies Centres nationally. One of these, the Eastern Australia Dementia Training Studies Centre (EATDSC) is located in NSW at the University of Wollongong and operates in conjunction with the Queensland University of Technology. The EATDSC has the following core activities: undergraduate curriculum development, postgraduate studies, scholarships, clinical workshops, guest lectures, and research and consultancy.

Another relevant initiative funded by the Australian Government has been a mapping exercise into dementia training curricula which has been undertaken across all health professions in Australia (LAMA Consortium, 2007).

There are clear opportunities for utilising the existing resources (educational, as well as skills and expertise) across program and jurisdictional boundaries. It is therefore imperative that the two levels of government work together to build on the resources already available, prevent duplication of effort, facilitate greater consistency in terms of quality and content of materials, and ensure value for money.

## **1.2 Service delivery context**

The policy context described above sets up, and responds to, the context in which services are delivered to people with dementia and their carers. As the NSW Dementia Action Plan clearly demonstrates, the number of people with dementia is increasing, and concomitantly, the breadth of service responses also needs to increase.

The impact of dementia on health services alone is substantial. For example, the most recent NSW Treasury budget estimates (NSW Treasury 2008) predicted that by 2011, persons aged over 65 will account for 38 per cent of New South Wales public hospital admissions and 52 per cent of bed days (by 2026 the over 65s will make up 20% of the NSW population, an increase of 87% from 2001). In a review of relevant literature, Wylie et al. (2005) cited research suggesting that older people with dementia (75 years+) are prone to greater hospital admissions (whether by illness, falls or critical incidents) and have longer lengths of stay, while those living in the community usually have some form of disability and use more medical services.

In addition to the projected increased numbers of people with dementia, there are a number of other factors driving a changing service milieu. Some of these include:

- improved awareness and early diagnosis of dementia;
- new pharmacological treatments;
- changing consumer preferences regarding accommodation and care settings;
- improved research into the efficacy of treatment and care options;
- greater appreciation of the role of informal carers, and recognition of them as legitimate services users in their own right;
- emergence of 'person centred care' as a philosophy that underpins service delivery; and
- increased pressures on acute hospital services.

These developments have led to a reframing of old services as well as the development of a range of new service models such as:

- prevention and early intervention services;
- multi-disciplinary care planning;
- case management;
- flexible respite options;
- carer education and support programs;
- aged-specific areas within or alongside emergency departments (e.g. ASET);
- dementia Extended Aged Care in the Home (EACH-D) packages; and
- Behavioural Assessment and Intervention Services (BASIS), which replaced the former Confused and Disturbed Elderly (CADE) units.

Alongside these developments, there are significant implications for the skill sets of people involved in delivering health, care and support services to people with dementia and their carers. New skills and knowledge have had to be acquired by staff within mainstream services as they adapt to these changing demographics, and specialist positions developed which can provide leadership across mainstream as well as dementia-specific services (e.g. dementia and delirium Clinical Nurse Specialists, Clinical Nurse Consultants and Nurse Practitioners within acute/community health services and residential aged care). The variety of health, care and support personnel who may be involved in the lives of a person with dementia and their carer is indicatively described in Figure 3 and Figure 4 on page 13.

### **1.3 Previous work**

A number of working groups and research papers have been conducted in recent years to consider the changing policy and service contexts, and the implications for resources, including education and training. This includes preliminary work for NSW Health from the Acute Care Dementia Education and Training Package Working Group (ACDETWG) who identified two types of target groups in for training in acute care services. Tables 1 and 2 outline in detail the two potential target groups and provide a useful definitional framework.

**Table 1 ACDETWG report: Staff who require basic level dementia education and training**

Non-Clinical Staff	Non-Contact Staff	Clinical Staff
<ul style="list-style-type: none"> <li>▪ Ward Clerk/Administration assistant</li> </ul>	<ul style="list-style-type: none"> <li>▪ Pastoral Care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Wardsmen</li> </ul>
<ul style="list-style-type: none"> <li>▪ Food Services</li> </ul>	<ul style="list-style-type: none"> <li>▪ Aboriginal Health Care Workers</li> <li>▪ Ethnic Health Care Workers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Assistants in Nursing</li> </ul>
<ul style="list-style-type: none"> <li>▪ Cleaners,</li> <li>▪ Handyman/Maintenance</li> <li>▪ Gardeners</li> </ul>	<ul style="list-style-type: none"> <li>▪ Volunteers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Diagnostic staff such as Radiotherapy, Pathology</li> </ul>
<ul style="list-style-type: none"> <li>▪ Security</li> </ul>	<ul style="list-style-type: none"> <li>▪ Interpreters</li> </ul>	<ul style="list-style-type: none"> <li>▪ Dieticians</li> </ul>
<ul style="list-style-type: none"> <li>▪ Transport</li> </ul>		<ul style="list-style-type: none"> <li>▪ Podiatrists</li> </ul>
<ul style="list-style-type: none"> <li>▪ Patient Services Assistants</li> </ul>		
<ul style="list-style-type: none"> <li>▪ Police</li> </ul>		<ul style="list-style-type: none"> <li>▪ Ambulance</li> </ul>

**Table 2 ACDETWG report: Staff who required advanced level dementia education and training**

Nursing*	Medical	Allied Health^
<ul style="list-style-type: none"> <li>▪ Enrolled Nurses (EN)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Juniors /interns</li> </ul>	<ul style="list-style-type: none"> <li>▪ Occupational Therapists (O/T)</li> </ul>
<ul style="list-style-type: none"> <li>▪ Registered Nurses (RN)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Resident Medical Officers (RMO)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Physiotherapists (P/T)</li> </ul>
<ul style="list-style-type: none"> <li>▪ Clinical Nurse Specialists (CNS)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Registrars</li> </ul>	<ul style="list-style-type: none"> <li>▪ Social Workers</li> </ul>
<ul style="list-style-type: none"> <li>▪ Clinical Nurse Consultants (CNC)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Career Medical Officers (CMO)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Psychologists</li> </ul>
<ul style="list-style-type: none"> <li>▪ Assistant Directors of Nursing (ADON)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Consultant Specialists</li> </ul>	<ul style="list-style-type: none"> <li>▪ Speech Therapists</li> </ul>

\* need to add Nurse Practitioners

^ need to add Diversional Therapists

Additional Australian research by Robinson and Street (2004) studying Aged Care Assessment Teams (ACATs) and interactive sessions for acute care nurses showed how these sessions helped with information sharing about existing community services and used clinical case studies to improve clinical knowledge.

Finally, the report by Nay et al. (2003) for the Victorian Department of Human Services outlines some key organisational questions for the conduct of education, training and staff development activities. This includes the following useful summary of the practical realities for many health services.

*“There is limited dementia specific content in undergraduate, postgraduate and continuing courses for professional service providers. Therefore, services often lack staff with a well-developed knowledge and understanding of the dementing process and appropriate interventions. Staff development is integral to EBP [Evidence Based Practice]. Does this facility ensure that ongoing training is available to staff that is relevant to their skills, work situations and training needs? Are space, time, staff and funding made available for staff development? Do*

*senior staff support staff development activities? Are rosters sufficiently flexible to permit staff to attend education? Does the facility offer any scholarships to assist staff to undertake further study? Is education valued in terms of position descriptions/ recruitment/ remuneration?" (Page 188)*

## **1.4 Scoping Survey Aims**

As agreed with NSW Health, the purpose of the scoping survey was to:

- Inform the Department of the current status of dementia specific education and training for health professionals in NSW; and
- Guide the Department where to direct one off training funds available under the NSW Dementia Action Plan 2007 – 2009 and where any future available investment would be the most effective.

This work will therefore provide an independent assessment of the current situation in NSW. It is a necessary step in moving forward with the dementia training agenda in NSW by providing recommendations for future funding of targeted and high value training projects. Specifically this work will examine existing training models and identify any gaps in dementia training for health professionals/workers in NSW. It will then feed into the development process for workforce training packages for health professionals/workers employed by NSW Health facilities.

## 2 Methodology

This section of the report outlines the project methodology which was developed in consultation with NSW Health. The two key elements of the study have comprised a scoping survey to capture the views of health professionals, carer organisations, dementia training providers and NSW Area Health Services, and an internet search of currently available training and educational resources.

The results of this project are presented in two sections. Section 3 presents the results of the scoping survey itself. Section 4 outlines the results of the internet search of current education and training opportunities.

### 2.1 Stakeholder interviewees

The survey process aimed to contact recognised dementia training providers and carer organisations in NSW and NSW Area Health Services, as well as one representative from the major health professional groups. NSW Health was consulted to produce a list of nominated contacts amongst these stakeholders.

The two main organisational stakeholders for this survey were the dementia training providers and NSW Area Health Services (AHS). The training providers were approached as they are best placed to provide a perspective on the current training available, as well as major gaps or deficits. NSW AHS were critical, as they were major end users of dementia training and education for improving the knowledge and skills of their staff. The views of people with dementia and their carers regarding the training needs of professionals were obtained through representative groups such as Alzheimer's Australia NSW and Carers NSW. Other peak organisations and major professional groups (e.g. medicine, nursing, and allied health) were also interviewed.

Project budget restrictions limited the survey of training needs to publicly funded health and care providers in NSW, and an upper limit of 30 interviews was set. A full list of stakeholder groups interviewed is provided in Attachment 1.

### 2.2 Scoping Survey

The scoping study survey comprised a nine (9) question telephone survey of relevant stakeholders in NSW. Representatives were sought from training provider organisations, carer organisations, health professional groups and Area Health Services.

NSW Health provided a draft set of survey questions, the final version of which is provided below (see Section 2.3). NSW Health also developed a schema for the dementia patient journey, which depicts the range of workforce groups and services that people with dementia and their carers may access and interact with along the dementia trajectory. This document provided the discussion framework for the survey (see Figure 3 and Figure 4).

The questionnaire was modular in design, asking the interviewee on their perspectives on the training needs of health professionals working in general health or community care services (e.g. nurses, general practitioners) as well as health professionals working in dementia specific or specialist services (e.g. dementia CNCs, psycho-geriatricians). It considered key training issues for different parts of the dementia patient journey.



Interviewees were also encouraged to suggest any written material or web-sites which may be of use to the project.

The information provided by individuals, as representatives of their organisations, has been kept confidential, and only grouped responses and non-identifying data have been used in this report.

### **2.3 Survey Questions**

Before the interview commenced, stakeholders were asked to briefly describe the dementia training activities undertaken by their organisation, or activities their organisation has participated in during the past 12 months. This was to obtain an understanding of the extent to which training was currently being accessed, as well as an opportunity to pick up training initiatives which would not otherwise have been identified through the internet search strategy.

The interview then continued with the following 9 questions;

1. In terms of priority, which health professionals should be targeted for dementia training?
2. In terms of providing high quality dementia care, what are the priority training needs?
3. Are there prerequisites for dementia training, such as addressing attitudes towards older people and willingness to identify and address individual care needs?
4. What are the current dementia education and training opportunities available? (For example: the training initiatives under Dementia as a National Health Priority, like the Eastern Australia Dementia Study Centre; training provided through Alzheimer's Australia NSW; other specific dementia training that can be accessed at state and/or AHS level like the acute care training module or the behavioural disturbance module)
5. What are the current barriers to training (e.g. access for rural and remote staff, workforce pressures)?
6. Where is training currently targeted – TAFE, University (undergraduate/postgraduate) or In-Service training?
7. What are the perceived gaps in dementia training in NSW? What topics are not covered in dementia training (For example: Do training packages cover some of these issues: people with younger onset dementia or people with intellectual disabilities as well as dementia; practical and safe ways to avoid escalating distress; and the assessment and management of pain for people with dementia?)
8. Who does not receive adequate dementia training?
9. If funds were available, how should the funding be allocated to achieve maximum benefit in terms of value for money, and to provide maximum benefit in terms of improved dementia patient care? (Including one-off investments in training, as well as training programs based on recurrent funding models).

### **2.4 An internet search of current education and training opportunities**

An internet search of current education and training opportunities available to the range of health professionals identified was also conducted, including University, TAFE, key training providers, and health professional groups. The search also considered web-sites, documents and reports

recommended by stakeholders during the interview process, as well as those which captured the views of people with dementia and their carers regarding the training needs of the services designed to assist them.

**Figure 3 Dementia Patient Journey - Part 1**

**Dementia – Patient Journey**

Stages in the patient journey	Staying Healthy	Diagnosis	Living with dementia	Getting support	Managing episodic illness	Getting support with challenging behaviour	Coping with the end of life
Service	Risk reduction	Diagnosis/ Assessment	Counselling/ information	Community Support	Acute care	Behavioural Support	Palliative care
<b>Workforce</b>	Primary care/GPs Health Promotion	Primary care/GPs	Primary care/GPs	Primary care/GPs	Primary care/GPs	Primary care/GPs	Primary care/GPs
		Community age care services <sup>1</sup>	Community age care services	Community age care services	Community age care services	Community age care services	Community age care services
		DASs	DASs	DASs			
		Memory clinics		Day Care services*			
		Geriatricians		Respite services*			
		Psycho Geriatricians					
		Neuropsychologists					
		Allied health <sup>2</sup>	Allied health	Allied health			
				Community care sector			
				Health/HACC			
				AANSW			
				CACPs/EACH			
					- Medical specialist - Allied health - Nurses - ASET - Ambulance - Discharge planners	Acute care for assessment and stabilisation	Acute care
					Dementia/delirium CNCs		
					MPSs		
					Justice health		
						SMHSOP - BASIS - DBMAS	
						Residential care staff	Residential care staff
						Day Care / Respite services*	Specialist Palliative Care services

<sup>1</sup> Eg. ACAT members, Dementia community nurses

<sup>2</sup> Eg. Audiologists, Clinical Dietetics (Nutrition), Occupational Therapy, Orthoptics (Optometry), Orthotics & Prosthetics, Physiotherapy, Podiatry, Psychology, Social Work, Speech Pathology

## Figure 4 Dementia Patient Journey - Part 2

### Additional specialised services for specific groups

**CALD:** interpreters, bilingual GPs, multicultural services, ethnic specific CACPs/EACH, ethnic specific residential care services

**ATSI:** Aboriginal vascular program, Aboriginal health liaison officers, AMSs, Aboriginal Home Care

**People with disability:** Disability services

\* = Provided by NSW Health and HACC

### Acronyms

AANSW	Alzheimer Australia NSW
ACATs	Aged Care Assessment Teams
AMSs	Aboriginal Medical Services
ASET	Age Care Services in Emergency Team
BASIS	Behaviour assessment and intervention services
CACPs	Community age care packages
CNCs	Clinical Nurse Consultants
DASs	Disability Advisory Services
DBMAS	Dementia Behaviour Management Advisory Service
EACH	Extended age care at home
GPs	General Practitioners
HACC	Home and Community Care
MPSs	Multi-purpose services
SMHSOP	Specialist Mental Health Service for Older People

### 3 Scoping survey results

The following section provides detailed analyses of the scoping survey responses for each of the survey questions. These data have been collated to avoid identifying any individual or organisation. The answers combine responses from health professionals, carer organisations, dementia training providers and NSW Area Health Services. Where appropriate, direct quotes from respondents have been provided.

The scoping survey interviews were conducted during May and July 2008. Interview subjects were initially nominated by NSW Health. Subjects were usually contacted by telephone, and upon their agreement to participate in the study, were emailed information about the project and the survey instrument to be discussed at a mutually agreeable time. The process took longer than initially anticipated, as in some cases it was difficult to locate and make contact with those nominated, or find an alternative representative.

Twenty four individuals participated in the scoping survey, with 22 interviewed via the telephone, and two individuals interviewed face to face. The sample was made up of 10 health professional group representatives (e.g. nurses, GPs, occupational therapists, neuropsychologists, social workers), 6 dementia training providers, 4 carer/peak organisations and 4 representatives from NSW Area Health Services (2 rural and 2 metropolitan). A small number of respondents, mainly in the health professional category, also canvassed their answers with colleagues prior to undertaking the scoping survey.

The average time to complete the telephone interview was between 30 and 40 minutes, and the collated answers to each question are provided below.

#### 3.1 Summary of responses to Question 1

*“In terms of priority, which health professionals or service providers should be targeted for dementia training?”*

One common reply to this question was that “everybody would benefit from training”. Respondents also indicated that training should look at understanding the prevalence and disease pathology of dementia, identifying cognitive deficits and managing challenging behaviours. The overwhelming majority of respondents indicated that all staff working in acute care settings should be targeted for dementia training. The clear message here was a focus on those providing front-line care across settings (acute, community and residential).

A substantial proportion of respondents also indicated that staffing in residential care facilities should be targeted for dementia training, especially in regards to behaviour management. This is especially important given that “dementia is a main cause of admission to nursing homes, and they all end up being in a dementia ward anyway”.

Several respondents also indicated that emergency department staff (nurses and medical staff) and emergency services staff (ambulance, fire and police) had a severe lack of knowledge about cognitive impairment and recognising the differences between dementia, delirium and depression (also known as the 3Ds).

Respondents also identified General Practitioners and community care workers (especially those providing home care, respite and day care services) as requiring more training in the early identification of cognitive decline, which could then facilitate appropriate diagnosis, treatment and support in a planned, rather than a crisis-driven manner.

Similarly, health interpreters were identified as requiring training in dementia, particularly given their role as the interface between people of cultural and linguistic diversity (CALD) and health professionals. While training has been provided to this group some years ago, additional training is needed, particularly given the ‘explosion of community (CALD) groups over the last ten years’, the turnover of staff, the number of sessional interpreters, as well as the extension of this service to HACC services (currently being piloted in Western Sydney).

Other health professionals and service providers that were identified by respondents, but to a lesser extent, included: new graduates and interns, hospital security staff, discharge planners, and medical specialists in psychiatry and rehabilitation.

Other important points raised by respondents included:

- the need for improved recognition between the health and care professionals of their respective skill sets e.g. many health professionals are unaware that Certificate III trained staff (Health Services Assistant) have training in person centred care;
- the need for more specialists to run cognitive rehabilitation/memory clinics; and,
- the availability of dementia services within an area/region is not clearly mapped out and/or readily accessible.

Finally, when answering the modular part of this question, nearly all responders said that dementia specialists and those working in specialist units were not a primary training priority, as they already had sufficient training and have adequate access to professional development via conferences and workshops.

### **3.2 Summary of responses to Question 2**

*“In terms of providing high quality dementia care, what are the priority training needs?”*

The most commonly identified training need related to improving the attitudes of health professionals and the health sector in general towards people with dementia. Several respondents indicated that attitudes towards people with dementia are generally poor, particularly in the acute sector which “struggles with the fact that aged clients are core business”. As a consequence, it was argued that training was needed to improve attitudes so that services and professionals could become more sensitive and tolerant towards people with dementia. Furthermore, several respondents indicated that more training was needed for health professionals to adopt a more person-centred approach to care.

The next major training priority was to provide relevant health professionals with a better understanding of dementia in terms of its prevalence and incidence, as well as the study of the following key components - early detection of cognitive impairment or decline with screening, the ability to distinguish between delirium and dementia, the management of challenging behaviours (in particular, behavioural and psychological symptoms of dementia [BPSD] symptoms) and techniques to communicate effectively with people with dementia.

The third most common training need was to provide health professionals with an understanding that carers and families are legitimate partners in care and in decision-making. It was argued that this should apply across the various stages of the disease pathway.

Another common training need related to increasing understanding and awareness of the impact that dementia has upon “the patient journey” and the importance of adapting clinical practice accordingly. For example, raising bed rails may be an appropriate way to prevent a patient from falling out of bed for patients without severe cognitive impairments, but this may actually increase the risk of a fall in dementia patients who are prone to wandering. Similarly, when teaching patients how to use particular aids or equipment, staff need to account for the short-term memory loss in dementia patients (i.e. patients will have difficulty recalling newly learned things). The

overriding message here was to ensure that clinical practice requires a flexible approach, not the application of “simplistic rules”.

Other issues brought up in response to this question included:

- a focus on care planning and management – looking at abilities and disabilities;
- the importance of one-to-one patient care;
- an understanding of how the physical ward or home environment affects the behaviour of people with dementia;
- the need for doctors to understand what can be done and achieved with community care; and,
- the need for more aged care workers and specialists.

### **3.3 Summary of responses to Question 3**

*“Are there prerequisites for dementia training, such as addressing attitudes towards older people and the willingness to identify and address individual care needs?”*

The majority of respondents to this question agreed that ageism was an important issue within the acute health system, and needs to be addressed in a fundamental way within dementia training.

The issue of ageism generated much comment from stakeholders. One respondent highlighted the importance of a process which enabled staff to examine values, attitudes and ethics and the philosophy of care, in a manner that facilitated comparisons of group and individual values, and aligned values and motivation. Other respondents noted the following aspects which could be addressed to combat ageist attitudes and practices:

- Person-centred care approach which underpins service delivery, and a holistic approach to care which recognises that ‘people are more than their disease’
- A flexible approach to the needs of older people
- A focus on the positives not the negatives of ageing
- Acceptance that ageing is inevitable and natural, and an appreciation of normal, and abnormal ageing
- Understanding that it is the dementia that is causing the problem behaviour, not the person – “the behaviour is not deliberate”
- A belief in patient and carer rights
- Not speaking down to older adults or using baby talk

Ageism was not considered to be such an issue in aged care or specialist dementia services, as there was the expectation that people working in these services were more likely to have a predisposition to care and respect for older people, and the required patience, enthusiasm and tolerance for clinical work in this area. However, recent qualitative research by Higgins et al. (2007), challenges the complacency in this area.

A number of respondents emphasised the need to improve general awareness of dementia amongst health and care service providers. This is so that staff are more attuned to potential early signs of cognitive decline, and are able to refer clients on for further assessment, diagnosis and treatment at an earlier stage of the dementing process. There was a clear understanding amongst stakeholders of the importance of early intervention for people with dementia, with a number raising the potential for new pharmacological treatments which may be of benefit, the importance of being able to plan legal and financial matters before cognitive decline progresses, and to ensure carers are provided with advice and support as soon as possible.

Some respondents also noted the value and importance of senior staff “role modelling” to junior staff in correct attitudes and behaviours in relating to older people on wards and in health care settings.

One respondent noted the importance of all health professionals to have cultural competency training, to assist in the provision of care of people with dementia from CALD backgrounds. This was considered particularly important given the large number of different community groups now living in NSW, the ageing profile of many of those groups, and the fact that the vast majority of these community groups access generic health and aged care services.

### **3.4 Summary of responses to Question 4**

*“What are the current dementia education and training opportunities available?”*

In response to question 4, the following list of current professional development training opportunities across the state was developed:

- Alzheimer’s Australia (NSW);
- Hammond Care Group - Dementia Services Development Centre;
- Eastern Australia Dementia Training Study Centre (EADTSC);
- The Bradford Dementia Group (International Site);
- TAFE NSW;
- NSW College of Nursing;
- The Nursing Group;
- Aged Care Assessment Teams Training;
- The New South Wales Institute of Psychiatry;
- University of Western Sydney Nursing Research;
- Anne Moehead, North Coast Area Health Service e-learning package;
- Rural Health Education Foundation;
- The Aged Care Channel; and
- the Helga Merl training package endorse by the Royal College of Nursing, Australia.

It should be noted that this list does not include local education and training initiatives run by AHS and ACATs, as well as individual conferences and professional workshops. Table 3 and Table 4 provide further details about these education and training opportunities. Additional information on the cost of training courses can be found on their web-sites.

### **3.5 Summary of responses to Question 5**

*“What are the current barriers to training?”*

Respondents consistently identified several key issues in response to this question. The major barrier was considered to be workforce pressures, with many health and care services suffering staff shortages (i.e. ‘the need to fill rosters every day’) that mean that attendance at training is not a priority. This was particularly an issue for rural services, with one respondent commenting ‘If I’m away at training, there is no one to replace me, and my clients don’t get a service for those days I am away’. In this context, staff turnover was also considered “a major challenge”.

Another key barrier was the lack of funding for courses, travel and accommodation (this applies variably across the health system). Again, this was particularly an issue for staff working in regional and rural areas, as training was usually provided in major centres some distance from their place of work, making access to those courses more expensive due to travel and accommodation costs.



A number of stakeholders commented on negative attitudes toward dementia training from management of mainstream services or hospital wards. That is, dementia training was not seen as a priority by many managers, particularly when dementia was not the primary reason for a person's presentation to that service or ward. The attitude appeared to be derived from the perspective of many health professionals and care providers that nothing can be done for people with dementia, leading one respondent to describe it as being a case of "you don't know what you don't know".

Underpinning these attitudes was a sense that dementia was not 'core business' for the acute health system, despite evidence of increasing numbers of hospital presentations. A number of respondents also stressed the importance of this being acknowledged at senior policy and management levels. This is articulated in a Dementia Care Services Plan, which would include the establishment of minimum standards for dementia care, implementation strategies and key performance indicators. An example of one policy under development is the Northern Sydney Central Coast Area Health Service (NSCCAHS) Dementia and Delirium Care Services Plan, which includes the requirements that all clients 65+ receive a screen at any access point, and are referred on for formal assessment if cognitive impairment is identified, and includes minimum standards regarding discharge planning and follow-up.

Stakeholders stressed the importance of face to face networking for the promotion of attitude change. In doing so they outlined a number of potential responses to address the general issue regarding a lack of time and a lack of staffing, including:

- Within training budgets, funds are included to release staff (i.e. back fill with casuals) so they can attend training. The approval of training funds to release staff was used in the recent Dementia / BPSD training with *NSW Health Transitional Behavioural Assessment and Intervention Service (T-BASIS) Units*. This approach required a lead time of about 3 months.
- Use a flexible method for the delivery for training - Online resources / multi-modal distribution. However, this takes development time and promoting the training packages is very important.
- Make greater use of case conferencing and reviews as a place for education and support. This requires a good team leader to conduct effective multi-disciplinary meetings.
- Use of a 'flying squad' of trained nurses to take over from staff to allow them to attend training.

Additional suggestions regarding professional training included:

- Tailor training for the appropriate setting (community, residential care and acute)
- Conducting sessions over two day periods so staff can come in and out of the training session, and are provided with reflective opportunities
- Build better linkages and frameworks to professional development pathways
  - reward staff undertaking self-directed learning
  - reward competency, not just attendance at training
  - creating a log-book to record professional development training and certificates
  - need to link training to registration and career advancement

Some respondents also raised access issues in relation to computers and the internet access. This included issues such as nurses not having a computer based way of working like GPs and some staff working in remote areas did not have good access to the internet.

### 3.6 Summary of responses to Question 6

*“Where is training currently targeted – TAFE, University (undergraduate/postgraduate) or In-Service training?”*

In response to Question 6, most respondents indicated that the bulk of professional development training was provided through in-services or 2-3 hour workshops under the auspices of AHS or professional bodies (e.g. Divisions of General Practice). A substantial proportion of respondents also indicated that some training took place in short courses provided by TAFE and Universities. Some respondents also mentioned the Eastern Australia Dementia Training Study Centre (EADTSC) at the University of Wollongong, Guest Lecture Series by name. This group provides these lectures at a number of venues via video conferencing.

For this answer, some respondents also commented on wider systemic issues:

- there is a need for more qualified and experienced people to provide training
- there is very little training in hospitals - “maybe once every three years in grand rounds”
- there is a need for more training in Residential Care.

A couple of respondents also questioned linking specialised dementia care and training within a mental health framework rather than in an aged care framework. This approach may limit a service’s responsiveness to all of a person’s needs by isolating the mental health issues in dementia from other aspects of ageing and functioning.

### 3.7 Summary of responses to Question 7

*“What are the perceived gaps in dementia training in NSW? What topic areas are not covered in dementia training?”*

In addressing this question respondents mentioned the overarching issues of increasing case complexity, the need for clinicians to be able to recognise signs of dementia, the impact of dementia on quality of life and the “patient journey”, the need for familiarity with cultural differences, restraint and safety issues, and improved communication styles with older people, such as spending time with people to fully explain issues and address concerns. A majority of respondents indicated that the major gap in dementia training is that many staff do not receive sufficient training in how to deal with and manage challenging behaviours in people with dementia.

Key topic areas for professional development training included:

- Dementia awareness training for everybody (core training)
- Cognitive assessment tools
- Delirium / dementia (looking for sudden changes in cognition)
- Communication with patients
- Preventing and managing challenging behaviour (including wandering, verbal and physical behaviour, aggression and restraint)
  - using psychological approaches rather than medication and restraint
  - identifying triggers (early intervention) and avoiding escalation using de-escalation procedures (In a recent workforce survey of Specialist Mental Health Service for Older People (SMHSOP)(workers), both managers and clinicians ranked BPSD as the highest training priority)
  - preventing elder abuse
- Cognitive capacity training for consent for surgery, advanced care planning
  - Important for each stage of dementia

- Ethical and legal issues
- Adapting your clinical practice e.g. prevention of dehydration, bed sores, falls

A clear focus was on the identification of cognitive impairment and behaviour management, given that these “issues are under-detected and therefore under-managed, and this can lead to problems with the patient care”. Understanding how to use assessment and diagnostic tools was also identified by a number of respondents. One respondent noted the importance of training in the Rowland Universal Dementia Assessment Scale (RUDAS), given the increasing number of people from CALD backgrounds that access generic health and care services such as GPs, ACATs and aged care services.

Additional topic areas for professional development training included:

- Younger people with dementia (the under 65s)
- Late stage dementia
- Pain management
- Care planning
- Comprehensive assessment
- Cognitive rehabilitation / memory clinics
- Person centred care and maximising the potential of people with dementia
- Early identification
- Quality use of medicines
- Cultural issues
- Stronger links between GPs and carers
- Greater appreciation of the role of carers as partners in care and decision-making, by health professionals
- People with intellectual disability, Down’s syndrome
- Dementia components for people with MS, stroke, and long term alcohol abuse
- Improvements to ward physical design / environment

### **3.8 Summary of responses to Question 8**

*“Who does not receive adequate dementia training?”*

Most responses to this question stressed the need to focus on front line workers (especially nurses). For example, it was argued that basic core training in dementia awareness needs to be “undertaken across the board”. Emphasis was made on multi-disciplinary training focusing on dementia awareness, adapting clinical practice, identifying cognitive impairment, appropriate communication, managing challenging behaviour, and restraint.

A large number of groups were identified as requiring training and included:

- Ambulance officers;
- Junior medical officers and new graduates working in the acute care sector;
- GPs and practice nurses (including those working in remote areas);
- New nursing and allied health graduates starting work and existing health professionals moving into the aged care sector (community and residential);
- Workers in residential aged care (especially in the management of challenging behaviour)
- Family carers;
- Support services workers – food services, cleaners and gardeners (who can observe and report on certain behaviours e.g. patients who are refusing food);
- Undergraduates in medicine, nursing and allied health;
- Health care interpreters.

Some wider community groups mentioned were also identified and included:

- community dementia awareness training for newsagents, butchers, bank clerks and other retail staff (who are often the first to pick up problems with memory and cognition in older people);
- training for lawyers in regard to checking cognitive capacity required for legal consent.

### **3.9 Summary of responses to Question 9**

*“If funds were available, how should the funding be allocated to achieve maximum benefit in terms of value for money, and to provide maximum benefit in terms of improved dementia patient care?”*

Respondents identified a diverse range of areas that funding should be allocated to in order to provide maximum improvements in dementia care whilst also being cost efficient.

A key theme has been the importance of utilising and building on existing resources, expertise and networks. The need for a supportive context in which to deliver training was also highlighted, and suggestions included mandatory training in dementia for AHS (such as required for Fire and OHS), and the adoption of an integrated model of care for people with dementia. This work would then set the agenda for dementia training and education within an AHS.

Another common theme raised by respondents related to the importance of bringing all the training activity together to be available at a central point (e.g. a dementia training website), where people could access available resources and dementia education opportunities.

A number of important and detailed suggestions were made, including: curriculum development for students, professional development for existing workers, support for new graduates in aged care, access issues, approaches to training, support staff, a focus on carers, and systemic and community issues. A summary of these suggestions is provided in Section 3.9.1 to 3.9.8 below.

#### **3.9.1 Curriculum development for students**

Curriculum development issues included creating greater depth in existing programs – “not just an elective in a crowded curriculum” or “more than one lecture”. The suggestions from respondents included:

- Increased emphasis on aged care in all health professional education, including Older Adult placements in addition to Adult and Child placements. It was argued that this model would ensure that new graduates will at least have exposure to and a greater understanding of the issues; some may also be inspired by the challenges in the area and see how positive improvements in health and functioning can take place in quality environments. This model is currently used in the United Kingdom for the professional training of psychologists.
- Increased emphasis during university and TAFE training for health professionals and care workers that aged care and dementia is core business for the health sector. For example, one clinician commented that if ‘I am getting new grads who think they are going to be looking after 30 year olds, that is a problem!’.
- A greater emphasis on recreational activities and lifestyle for people with dementia in Aged Care Workers (Certificate III), Recreational Activities Officer and Diversional

Therapist training. This unit of study would be more focused on the topic area of dementia and refer to medications, lifestyle, challenging behaviours and activities therapy (e.g. life stories).

- Develop a new TAFE training package linking Home Care, Disability and Aged Care.
- Inclusion of case management and care co-ordination skills development.

### 3.9.2 Professional Development for existing dementia workers

For the professional development of existing workers a number of positive suggestions were made. These include:

- Create a supervision/mentorship program for existing dementia workers providing support and education; and the use of case review and planning process as a way into care services and sites. Case review and planning does occur within some service contexts - e.g. ACATs, and through the more recent Council of Australian Governments (COAG) Long Stay Older Patients initiative in developing transitional care services like Aged Care Services in Emergency Teams (ASET) and Acute to Aged Related Care Services (AARCS), however there are clear opportunities for this to be more a widespread practice. There are clear benefits for health professionals and care providers in utilising this approach, as well as for clients and their families.
- More support for new graduates (nursing and allied health) working in the aged care sector (residential and community) by establishing a multi-disciplinary training/professional development training program, using a PHC model – i.e. “we need to break down the professional silos”.
- Greater opportunities for professional associations to support GPs and junior medical officers.
- Facilitate a network of ‘change champions’ which could work within, and across health and aged care services who can educate as well as facilitate the implementation of changed care practices within these contexts.
- Providing supported placement opportunities for staff within existing organisations (e.g. acute ward staff working in ACATs, or ASET of their local hospital) as well as between service contexts (e.g. residential aged care and acute settings). This would include a structured educational and mentoring component, and facilitate knowledge transfer and a better understanding of the issues facing these different care contexts (e.g. staffing profiles and pressures, regulatory environments, the availability of resources). This would facilitate closer links between the services and a better understanding of each of their challenges and lead to more efficient and effective care pathways. Such an approach would assist in improving the patient / resident journey.

### 3.9.3 Improving access to education and training

The following suggestions were made to improve access to training funds and support:

- Create a scholarship program in dementia (e.g. ten training scholarships per year), providing assistance with funding to release staff from their positions.

- Provide of a flexible pool of funds for dementia training which can be utilised for providing relief / backfill staff associated with training and educational opportunities, as well as covering the costs of training, travel and accommodation.
- Establish a 'flying squad' of trained nurses to take over from staff to allow them to attend training.

### 3.9.4 Training Approaches

The following training approaches were identified by respondents:

- Bring together all the work has been done in NSW / Australia similar to the recent Federal Government document – the *Dementia Resource Guide* produced by the National Ageing Research Institute (NARI) (Web-site: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>). This work would focus on professional development, self-learning packages available on the internet, especially tools for screening and assessment of cognitive impairment. This would require some additional resources to establish, promote and maintain. The need for incentives to undertake these self-learning courses would also need to be considered.
- Adapt an action and participative research or quality improvement model designed to improve care outcomes in different settings using a training component to address local needs.
- Build better linkages and frameworks to professional development pathways
  - reward staff undertaking self-directed learning
  - reward competency, not just attendance at training
  - creating a log-book to record professional development training and certificates
  - need to link training to registration and career advancement
- Establish a network of 'change champions', as described above in 3.9.2.

### 3.9.5 Support staff

For support staff (cleaners, gardeners and food services) a key suggestion is to provide a dementia awareness program, including understanding of the disease pathway and how it can affect behaviours. Table 1 provides a list of staff who would require such training. "In my experience these staff members are keen to learn; they just need permission to attend. They would attend in numbers."

### 3.9.6 A focus on carers

Suggestions for giving a greater role for carers, as care partners, included:

- Acknowledgement of the role of carers as partners in care and in decision-making. "Communication in general needs improvement. Hospital is an uncomfortable and alien environment for many carers. They are often required to be at the bedside at the drop of a hat and are frequently given little information and involved in care planning after decisions have been made."

- More information and educational support for carers and families by conducting regular family meetings
- In addition to health professionals, provide funding for training programs for carers, to enhance their capacity to continue to undertake the caring role

### 3.9.7 Systemic Issues

Suggestions made at the level of the health system included:

- Develop an integrated model of care for people with dementia in acute care, which then sets the framework and agenda for dementia training and education within each AHS. This model would include screening, basic and comprehensive assessment, establishment of protocols regarding care pathways, and minimum standards for discharge planning, follow-up etc.
- Need for primary prevention approach, which prevents catastrophic events, and keeps people healthier for longer.
- Dementia should be “core business” for all and this should be incorporated into AHS strategic plans.
- Mandatory training in dementia across health and care services in NSW (such as required for fire, and occupational health and safety). For example, one respondent indicated that “we have many more disasters with people with dementia than we do fires”.
- Fund additional training positions for Geriatricians, Psycho-geriatricians, and Dementia CNCs to improve service provision, but also to assist with staff supervision and case review.
- Additional resourcing for community neurology and psychogeriatric teams for each AHS.
- Improved planning of care environments so that facilities are developed which minimise risk of harm, provide orientation cues, prevent wandering and enhance the abilities of the person with dementia – “To create cognitively enriching environments”. This could be achieved by incorporating dementia design principles currently available in residential aged care, and the inclusion of a consumer/carer representative on the planning team.

### 3.9.8 Community Issues

Community dementia training issues included:

- Wider community training tackling ageism and negative stereotypes, as well as a respect for older people advertising campaign.
- Community dementia awareness training for newsagents, butchers, bank clerks, and other retail staff.
- Training for lawyers in regard to checking cognitive capacity required for legal consent, and
- Dementia itself needs a more positive image. “Everything portrayed in the media is negative (e.g. people wandering off, abusing, harming their families etc). There should

be more emphasis on what people with dementia can do rather than what they cannot. There are people with dementia who are still contributing significantly to society but we seldom hear of them”.

### **3.10 Summary of responses**

A total of 27 stakeholder groups were interviewed. An overall summary across all responses is captured in the following dot points.

- A key message was the importance of targeting those providing front-line care across acute, community and residential care settings. A list of key groups was identified (e.g. ambulance officers, security staff, new graduates).
- Everyone working in the health system could benefit from dementia awareness training.
- Key training study topic areas were identified (e.g. distinguishing between dementia and delirium, and preventing and managing challenging behaviours).
- Important concerns about ageism and negative attitudes/behaviours in the health system and the wider community were raised.
- A list of current training opportunities was created and barriers to training were identified - the most common being a lack of time and staff, and a lack of access to funds.
- A detailed list of funding suggestions was developed for further analysis.



## 4 Internet search into current education and training opportunities in dementia

The internet search located a number of useful training resources for education and professional development. These are presented in the following four tables. These tables have been divided into the following topic areas: Accredited Training Courses (as mentioned by respondents); Professional Development Workshops; Online Education / E-Learning; and additional resources on the internet.

**Table 3 Results of the internet search - Accredited Training Courses (as mentioned by respondents)**

Organisation	Training Offered	Web-site	Audience(s)
Nursing Group	Certificates III / IV in aged care	<a href="http://www.nursinggroup.com.au/Training&amp;Education.html">http://www.nursinggroup.com.au/Training&amp;Education.html</a>	Nursing (Professional Development)  Certificate courses for Aged Care Workers
The College of Nursing	Continuing and Distance Education in Nursing	<a href="http://www.nursing.edu.au/CourseS/">http://www.nursing.edu.au/CourseS/</a>	Courses for enrolled and registered nurses
The New South Wales Institute of Psychiatry	Graduate Certificate in Mental Health (Older Person) Graduate Diploma of Mental Health (Older Person)	<a href="http://www.nswiop.nsw.edu.au/pages/courses/postgradcourses.php">http://www.nswiop.nsw.edu.au/pages/courses/postgradcourses.php</a>	Certificates / Diplomas for Mental Health workers
Hammond Care Group, Dementia Services Development Centre	Training includes: Developing a clear philosophy of care; Teamwork; Assessment leading to a clear grasp of the issues; Care planning; Managing specific issues such as challenging behaviours; Environment design and modification	<a href="http://www.hammond.com.au/dsdc/">http://www.hammond.com.au/dsdc/</a>	All health professionals  "Dementia Care Essentials" for Aged Care Workers – no web-site acknowledgement see <a href="http://dementia.acswa.org.au/">http://dementia.acswa.org.au/</a> for equivalent national training
TAFE NSW	Certificates III / IV in nursing and aged care	<a href="https://www.tafensw.edu.au/howex/servlet/Course?Command=GetAdvancedSearchResult&amp;WindowName=&amp;cen=null&amp;URL=%2Fservlet%2FCourse%3FCommand%3DGetSimpleSearch&amp;SemesterDropList=20082&amp;VTEXT1=aged+care&amp;VLOCATION=&amp;VLOCATION=&amp;VLOCATION=&amp;TPs=&amp;VCAREER=&amp;VINDUSTRY=&amp;VFOE=">https://www.tafensw.edu.au/howex/servlet/Course?Command=GetAdvancedSearchResult&amp;WindowName=&amp;cen=null&amp;URL=%2Fservlet%2FCourse%3FCommand%3DGetSimpleSearch&amp;SemesterDropList=20082&amp;VTEXT1=aged+care&amp;VLOCATION=&amp;VLOCATION=&amp;VLOCATION=&amp;TPs=&amp;VCAREER=&amp;VINDUSTRY=&amp;VFOE=</a>  <a href="https://www.tafensw.edu.au/howex/servlet/Course?Command=GetAdvancedSearchResult&amp;WindowName=&amp;cen=null&amp;URL=%2Fservlet%2FCourse%3FCommand%3DGetSimpleSearch&amp;SemesterDropList=20082&amp;VTEXT1=nursing&amp;VLOCATION=&amp;VLOCATION=&amp;VLOCATION=&amp;TPs=&amp;VCAREER">https://www.tafensw.edu.au/howex/servlet/Course?Command=GetAdvancedSearchResult&amp;WindowName=&amp;cen=null&amp;URL=%2Fservlet%2FCourse%3FCommand%3DGetSimpleSearch&amp;SemesterDropList=20082&amp;VTEXT1=nursing&amp;VLOCATION=&amp;VLOCATION=&amp;VLOCATION=&amp;TPs=&amp;VCAREER</a>	Courses for nurses and aged care workers

<b>Bradford Dementia Group</b>	* International site *  Short Courses, Certificates and Diplomas	<a href="http://www.brad.ac.uk/health/dementia/">http://www.brad.ac.uk/health/dementia/</a>	Certificates / Diplomas for all health professionals  Distance education available
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**Table 4 Results of the internet search - Professional Development Workshops**

Organisation	Training Offered	Web-site	Audience(s)
<b>Eastern Australia Dementia Training Study Centre (EADTSC)</b>	Clinical Workshops and Guest Lectures	<a href="http://dementia.uow.edu.au/activities/clinical-workshops.html">http://dementia.uow.edu.au/activities/clinical-workshops.html</a>  <a href="http://dementia.uow.edu.au/activities/quest-lectures.html">http://dementia.uow.edu.au/activities/quest-lectures.html</a>	All health professionals
<b>Alzheimer's Australia</b>	Customised education and professional development	<a href="http://www.alzheimers.org.au/content.cfm?topicid=188">http://www.alzheimers.org.au/content.cfm?topicid=188</a>	All health professionals and aged care workers

**Table 5 Results of the internet search - Online Education / E-Learning**

Organisation	Training Offered	Web-site	Audience(s)
<b>The Aged Care Channel</b>	Learning Resource Kits in dementia management and behaviours	<a href="http://www.agedcarechannel.com.au/ACC_LRK.html">http://www.agedcarechannel.com.au/ACC_LRK.html</a>	Nursing (Professional Development)  Certificate courses for Aged Care Workers
<b>Aged Care Assessment Teams</b>	Self-direct learning packages for ACATs	<a href="http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-acat-acap-training.htm">http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-acat-acap-training.htm</a>	Self-directed learning for ACAT members – Induction / Orientation
<b>EADTSC: Dementia Education Online</b>	Online Training Modules in dementia incidence, assessment and communication	<a href="http://dementia.uow.edu.au/activities/education-online.html">http://dementia.uow.edu.au/activities/education-online.html</a>	All health professionals
<b>Rural Health Education Foundation</b>	Dementia - Carers and Families; Quality Use of Medicine in Dementia Care; Dementia, Mental Health and Neurological Co-morbidities; Dementia and Physical Co-morbidity; Dementia - Assessment and Diagnosis	<a href="http://www.rhef.com.au/programs/groups.html#Gerontology">http://www.rhef.com.au/programs/groups.html#Gerontology</a>	General Practitioners and other health professionals (Professional Development)
<b>Stanford Geriatric Education Center (SGEC)</b>	* International site *  Online Training Modules in culturally and linguistically diverse health care and improved communication with older people	<a href="http://sgec.stanford.edu/training/">http://sgec.stanford.edu/training/</a>	All health professionals

<b>Anne Moehead, North Coast Area Health Service</b>	NSW Health supported training package into the assessment and management of older people	<a href="http://elearning.ncahs.health.nsw.gov.au/">http://elearning.ncahs.health.nsw.gov.au/</a>	All health professionals
<b>Palliative Care Australia (PCA)</b>	Training Resources for the Guidelines for a Palliative Approach in Residential Aged Care  <i>PCA also conducts palliative care workshops "Active Learning Modules" to a certificate level</i>	<a href="http://agedcare.palliativecare.org.au/Default.aspx?tabid=771">http://agedcare.palliativecare.org.au/Default.aspx?tabid=771</a>  <a href="http://pallcare.org.au/Default.aspx?tabid=1718">http://pallcare.org.au/Default.aspx?tabid=1718</a>	All health professionals

**Table 6 Results of the internet search - additional resources on the internet**

<b>Organisation</b>	<b>Training Offered</b>	<b>Web-site</b>	<b>Audience(s)</b>
<b>Helga Merl training package (endorsed by the Royal College of Nursing, Australia)</b>	"Time to Think About Dementia and Aged Care" 4 set CD training package	<a href="http://www.rcna.org.au/site/endorsement.php">http://www.rcna.org.au/site/endorsement.php</a>	Nursing (Professional Development)
<b>Attorney General's Department, NSW</b>	Capacity Toolkit - What is 'capacity'? How do I decide whether a person has the capacity to make their own decisions?	<a href="http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_Diversity_Srvces.nsf/pages/diversity_services_capacity_toolkit">http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_Diversity_Srvces.nsf/pages/diversity_services_capacity_toolkit</a>	All health professionals (Professional Development)
<b>University of Western Sydney Nursing Research</b>	Family Information Booklet for Family Carers of People with Dementia	<a href="http://future.uws.edu.au/_data/assets/pdf_file/0008/7100/INFORMATION_Dementia_Web_Ready.pdf">http://future.uws.edu.au/_data/assets/pdf_file/0008/7100/INFORMATION_Dementia_Web_Ready.pdf</a>	Carer Resource
<b>Ageing Research Online</b>	Latest information on dementia research in Australia	<a href="http://www.aro.gov.au/dementia.htm">http://www.aro.gov.au/dementia.htm</a>	All health professionals (Information Resources)
<b>Eastern Health</b>	Cue cards to assist with cross cultural communication between patients and staff	<a href="http://www.easternhealth.org.au/language/cueCards/cards.asp">http://www.easternhealth.org.au/language/cueCards/cards.asp</a>	All health professionals (Communication Resources)
<b>Julia Poole, Royal North Shore Hospital</b>	Slideshow, Clinical Algorithm – "Nursing management of disturbed behaviour in older people"	<a href="http://alzheimers.org.au/upload/Dementia_Delirium_Julia_Poole.ppt#279,1,Dementia%20and%20Delirium%20-%20the%20unrecognised%20connection">http://alzheimers.org.au/upload/Dementia_Delirium_Julia_Poole.ppt#279,1,Dementia%20and%20Delirium%20-%20the%20unrecognised%20connection</a>	All health professions
<b>National Cross Cultural Dementia Network</b>	Web resources, network	<a href="http://www.alzheimers.org.au/content.cfm?topicid=358">http://www.alzheimers.org.au/content.cfm?topicid=358</a>	Assists with service delivery for culturally and linguistically diverse communities
<b>Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities</b>	Toolkit and materials for delivery of dementia awareness raising, information and education sessions	<a href="http://www.alzheimers.org.au/content.cfm?infopageid=4654">http://www.alzheimers.org.au/content.cfm?infopageid=4654</a>	Assists with service delivery for Aboriginal and Torres Strait Islander communities

<b>Understanding Younger Onset Dementia</b>	Education booklet	<a href="http://www.alzheimers.org.au/upload/QDC_YOD.pdf">http://www.alzheimers.org.au/upload/QDC_YOD.pdf</a>	All health professionals and carers
<b>Centre for Education and Research on Ageing (CERA)</b>	Dementia awareness training for staff working at Gosford City Council  <i>CERA also provides a number of training packages for professionals working in residential and community care, including information for GPs (For some training packages payment is required)</i>	<a href="http://www.cera.usyd.edu.au/resources_other_gosford.html">http://www.cera.usyd.edu.au/resources_other_gosford.html</a>  <a href="http://www.cera.usyd.edu.au/resources_manuals.html">http://www.cera.usyd.edu.au/resources_manuals.html</a>	People in customer service roles
<b>Home Modification Information Clearinghouse</b>	Brings together information on home modification in Australia	<a href="http://www.homemods.info/">http://www.homemods.info/</a>	Health professionals especially occupational therapists (Information resources and networking)
<b>Queensland Health</b>	Training materials provided online for the CHCAC15A – Part of Certificate III in Home and Community Care	<a href="http://www.health.qld.gov.au/hacc/CertIII_Compencies.asp">http://www.health.qld.gov.au/hacc/CertIII_Compencies.asp</a>	Home Care / Community Care / Aged Care Workers

In addition to the information sources found here, two points are worth mentioning:

1. The newly published Australian Government document – the *Dementia Resource Guide* produced by the National Ageing Research Institute (NARI) (Web-site: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>) has a section on training, which could be improved by reference to the sources found here.
2. It is interesting to note the absence of carer education and support on-line education / e-learning packages available in Australia. One possible model would be the DementiaGuides Inc. in America by Dr. Kenneth Rockwood and his team (see Web-site: <http://www.dementiaguide.com/index.php>). At this web-site people can track their dementia symptoms and share information as well as received online education. This model could be adapted to computer literate carers who would like to monitor their partner or family member as well as record the positive and negative aspects of their own caring role (for example, measuring the clinically important issues of fatigue, stress, and depression).

## 5 Discussion

The following section discusses the key methodological issues and themes that emerged during the course of the study.

### 5.1 *Methodological issues*

In terms of methodology, the survey worked well, eliciting many useful responses. The modular design of the survey, dividing it into two parts – i.e. health professionals working in general health or community care services (e.g. nurses, general practitioners) and health professionals working in dementia specific or specialist services (e.g. dementia CNCs, psycho-geriatricians) - did not seem to add value to the interviews. Most respondents agreed that health professionals working in dementia specific or specialist services were being catered for by professional conferences and workshops, and do not represent the main area of training need. However, a few respondents did comment “that we could do with a few more of them”.

There are some limitations of this scoping survey project that warrant discussion. Firstly, the data were collected utilising a telephone survey comprising of nine open-ended questions. This technique was appropriate for the exploratory purposes of this study given that it facilitated in-depth and detailed responses from stakeholders. However, it should be acknowledged that the interviews involved the collection of qualitative data (i.e. unstructured responses), which may be susceptible to some degree of subjectivity or bias during analysis and interpretation. In a sense we are captive to our sample (for example, training providers made up 25% of the sample and their views as a group have more weight, than a single health professional interviewee from occupational therapy). Also some interviewees may be focused primarily on their own working situation, rather than looking at the system as a whole.

Furthermore, interview methodologies generally are time consuming to undertake. One of the main difficulties we found was the time it took to locate relevant stakeholders and schedule the interviews. These issues limited our sample size to 27 stakeholder groups which does not provide the widest representation of the views of all health professionals working in NSW Area Health Services (for instance, only 4 out of the 8 AHS were interviewed). The small sample size also limited the opportunity to adequately compare responses between the different health professional groups, dementia training providers, peak organisations and NSW Area Health Services.

As a consequence, we believe that it would be useful to further validate the present findings. This could be achieved by presenting these results for discussion at conferences or dementia forums, as well as assessing them through a clinical advisory group. This approach would also have the added advantage of gaining more stakeholder support for the dementia training agenda.

### 5.2 *Key messages*

Two key messages emerge from the outcomes of the scoping survey and the internet search, all of which have implications for the training and education of health and care professionals:

1. Dementia is core business for the health system and this needs to be reflected at the systemic level
2. The philosophy of person centred care should underpin the delivery of health and care services

### 5.2.1 Dementia is core business for the health system

Historically, the provision of dementia services has been patchy, and people with dementia regarded as a small subset of the general population. Over the last two decades, however, there has been an increasing awareness of, and research into, the impact of the projected increase in numbers of people with dementia on the formal health and care systems. The research cited in Section 1.2 above, demonstrating that older people with dementia (75 years+) are prone to greater hospital admissions (whether by illness, falls or critical incidents) and have longer lengths of stay, while those living in the community usually have some form of disability and use more medical services, is echoed by the feedback from stakeholders during the scoping survey process.

The experience of stakeholders is that older people, and people with dementia, represent an increasing proportion of the client base in generic health and community services, particularly as more service options become available to enable them to continue living in the community. A number of policy frameworks have been developed to address these shifting client profiles, including the NSW Dementia Action Plan and the NSW Carers Action Plan. However, the mindset of those delivering, and planning for these mainstream services does not appear to have adapted to the changing reality, with the consequence that many people with dementia do not receive optimum care, and indeed are often at risk within these service settings.

The overwhelming response from stakeholders was that these mainstream services need to reframe the way in which they provide care and support. They should not abrogate their responsibilities for the client by simply referring on to specialist services.

### 5.2.2 System level responses

In order to achieve a culture and understanding of dementia being core business, stakeholders identified the need for a systemic driver, which would encourage and enforce services to be developed and implemented more responsively to the needs of people with dementia and their carers. As the research shows, (e.g., Nay et al 2003, described previously in Section 1.3), support from senior staff and organisational management is crucial to advancing the dementia training agenda. Suggestions from stakeholders included having imperatives in place (e.g. key performance indicators), for AHS to demonstrate a planning process and evidence of its implementation, including explicit targets set for skill/service mix within each Area. It was argued that this would assist in a cultural shift at the most senior levels of management of health and care services, which would then flow down to those in the front-line of service provision. A corollary of this would be the support of an education and training agenda and allocation of resources to meet the needs identified.

It is clear that this is part of the agenda for the NSW Dementia Action Plan, with its focus on service planning under Priority Area 1. However, it was apparent that this information had not yet filtered down to key stakeholders within the Areas at the time of conducting the scoping survey. It is understood that the NSW Strategic Plan for Palliative Care is currently being written with an emphasis on integration of palliative care into core business of all health services, including performance indicators written into the contracts of the AHS chief executives and key personnel. This could prove a useful model for dementia care, following the completion of the Dementia Service Planning Frameworks.

It was also found that there is a need for the development of a basic screening tool for cognition to be used by all health professionals coupled with a set of clear referral pathways if further action is indicated. Here the clinical algorithm developed by Julia Poole at Royal North Shore

Hospital could prove useful. Similarly, the Older Person Acute Care (OPAC) model (Peek et al., 2007) provides a useful model for the screening and management of people with dementia and delirium who enter emergency and acute services. The model includes key values like respect, dignity, choice, communication, involvement of older people and carers, as well as emphasizing key clinical symptoms like continence, dementia, mental health, mobility, nutrition and hydration, pain, palliative care and pressure sores. This is underpinned by a person centred care philosophy emphasising a multi-disciplinary approach with time for critical reflection to drive practice improvement.

Mandatory training for all staff in dementia and delirium was raised by a number of stakeholders as a means of embedding within health services the concept of dementia being core business. This can be supported by a recent paper on the subject (e.g., Millsen et al 2006).

### **5.2.3 The philosophy of person care should underpin the delivery of health and care services**

The current health and care service systems are founded on distinct professional, program or funding boundaries, and do not optimise outcomes for the clients of their services who have complex care and support needs. As one stakeholder noted, 'the acute wards are set up for moving people through'. A patient or person centred approach places the individual at the forefront, and seeks to provide assistance in a manner that addresses their needs and circumstances, rather than that of the service provider or health professional. Person centred care extends on this approach by aiming to improve the person's well-being. It requires consideration of the person holistically, not just focussing on the primary reason for presentation to a health service, for example, considering their feelings or any underlying physical problems ('stressors'), which may often be expressed as BPSDs (e.g. crying, screaming, pacing, agitation). These stressors can then be identified and examined (i.e. what has led to these feelings) with a view to eliminating, modifying or reducing them in order to improve a person's level of well-being.

Stakeholders identified a number of benefits of this approach being applied to people with dementia:

- Facilitates co-ordinated and coherent health and care planning;
- Services are tailored to meet the specific needs and circumstances of the person with dementia;
- Greater focus on maintaining function and optimising opportunities for independence as much as possible;
- Ensures needs of carers are taken into account.

A number of benefits for staff and services were also identified:

- Enhances learning opportunities by working within a multi-disciplinary team;
- Breaks down professional and program boundaries, and improves understanding of related health and care services;
- Increases opportunities for professional mentoring;
- Tackles ageist attitudes that may be amongst some health and care professionals;
- Facilitates a culture of evidence-based practice and continuous improvement.

It was acknowledged that while it is difficult to implement a person centred care approach in some acute care settings, a number of stakeholders argued that it was still necessary, in order to avoid the risk of harm, prevent catastrophic events and keep people healthier longer.

### **5.3 Implications for a dementia education and training agenda**

It is clear from the stakeholder surveys and the internet search that there is much dementia training already available to health and care providers in NSW. However, not everyone who needs training is currently receiving it, there are key gaps in the course content, and access to training opportunities remains problematic.

#### **5.3.1 Who should receive training?**

The survey revealed a hierarchy of audiences for dementia education and training. The main message from stakeholders was that people providing front-line care across acute, community and residential care settings need to have better access to training, as 'they have the most impact on lives of older people and people with dementia'.

Within this group, there was a definite priority on training for staff in acute hospitals, particularly nurses, and those working in emergency departments. The key reasons for this focus are the high turnover of staff, time pressures, the skill set (and interest) of staff, and the impact of a transitory and overstimulating environment on the person with dementia. New graduates were also nominated, due in part to the limited exposure to dementia within the crowded curricula, and the mismatch between their expectations as to who they will be providing care to, and the reality. Security staff were also identified as requiring training, as these individuals are often called upon for assistance with people with aggressive behaviours.

Staff working in residential aged care were also identified as key audiences for training, given the substantial proportion of residents who have cognitive impairment. Community care workers and General Practitioners were also nominated as requiring training, because of the limited mentoring opportunities available to these predominantly lone operators, and their potential to identify early on if a person is starting to show signs of cognitive decline and ensure appropriate referrals are made.

Carers of people with dementia were also mentioned by stakeholders as requiring training, although to a lesser extent than those groups just noted. This could be a reflection of the predominance of health and care stakeholders involved in the survey, and the fact that survey clearly stated that its focus was on health professionals.

Staff working in services which target people of culturally and linguistically diverse backgrounds (CALD), as well as indigenous communities, were also identified as requiring a specific training focus. Several respondents noted the importance of understanding cultural sensitivities around dementia, in order to target information and support appropriately. Similarly, staff working with indigenous communities need to have an appreciation of the different aetiology and pathology of dementia which is experienced within these communities and the associated care and support needs. The importance of the general community receiving information about dementia was raised by a number of respondents, as this was seen as critical to combat negative and ageist stereotypes and attitudes, improve community understanding of and support for people with dementia and their carers, and encourage prevention and early intervention. Lawyers and bank clerks were also specifically mentioned due to their role in preventing financial abuse of people with dementia.

#### **5.3.2 What should be included?**

The survey and internet search revealed a number of critical elements that were not adequately addressed within the training that is presently available, which are described below.



Early detection of cognitive decline and impairment was considered a critical element for inclusion in dementia training, especially for GPs and community care staff. There was a clear understanding amongst stakeholders of the importance of early intervention for people with dementia, with a number raising the potential for new pharmacological treatments which may be of benefit, the importance of being able to plan legal and financial matters and advanced care directives before cognitive decline progresses, ensuring that carers are provided with advice and support as soon as possible.

A recurring theme amongst stakeholders was the importance of health and care providers having a greater appreciation and recognition of carers as partners in decision-making and care of a person with dementia. Training also needs to incorporate communication techniques and facilitation skills to enable carers to actively contribute in decision-making processes, such as case conferencing and multi-disciplinary team meetings.

The ability of acute hospital staff to distinguish between dementia and delirium was also raised. There are already a number of delirium guidelines which have been developed, and it is understood that NSW Health, using AHMC funding, has recently contracted the EADSTC to develop National Guidelines in Delirium. It will be imperative that these national Guidelines are actively promulgated and incorporated into existing training programs and opportunities implemented, to assist staff make the distinction between the two and respond appropriately.

The prevention and management of challenging behaviours, particularly in the acute hospital setting, was raised by a large number of stakeholders. Many cited examples of occasions they had witnessed unnecessary restraint (chemical as well as physical) used to deal with aggressive behaviours, either because the staff did not know how to prevent the escalation of behaviours, or out of concern that the patient might harm themselves or others. Implicit in any training would be an opportunity for staff to reframe their understanding of what constitutes challenging behaviour, and to not apportion blame to the person with dementia. For example, wandering may be a normal behaviour for a person with dementia, as they seek to orientate themselves to a new and unfamiliar environment. The problem is they are unable to remember or recognise any of the landmarks or people, and so the wandering can be repetitive or excessive. Thus, it is more the context which makes the behaviour a challenge for staff that are responsible for managing the person with dementia. Similarly, there should also be a focus on planning and prevention strategies to minimise the risk of aggression. There is much talk within health services about 'zero tolerance to aggression' and the importance of protection of workers. However, it is important to recognise that this response is not appropriate for confused older people, for whom the aggression can often be prevented if the proper strategies are in place.

Communication techniques were identified as key issue which needs to be addressed between providers and clinicians, as well as with clients and their carers. This includes ensuring that busy clinicians take time to fully explain issues and address the concerns of their patients.

The acute hospital environment operates in a fixed manner, with quite clear rules and guidelines which do not always accommodate the requirements of people with dementia. As a consequence, there is a need for clinicians to be able to adapt clinical practice and provide more flexible responses to individual needs. This is a feature of many services in the aged care sector, and there are opportunities for cross-fertilisation of ideas and strategies between the two sectors.

Case management and effective case review skills were also identified as being critical in ensuring sound care and management of people with dementia. This was a particular need when supporting people of CALD backgrounds, who find it difficult to negotiate and co-ordinate the service system. As one stakeholder commented, "(i)f you don't have the language, you can't negotiate ...you need someone with inside knowledge, someone who can coach you, so you can break into the system". Working in a multi-disciplinary team environment was also identified as a

required skill set, particularly for clinicians used to working individually in their discipline-specific field.

A recurring theme amongst respondents was the importance of combating ageism and negative stereotypes, as this was a key issue that undermined the ability to deliver training, and therefore good care, to people with dementia. Ageist attitudes were apparent at a number of levels, including:

- Direct care workers (e.g. nursing staff), many of whom, it was felt, were more interested in those patients with an acute care need, which had more immediate responses and resolutions, rather than working with older people with complex health and care needs. One respondent commented that the Emergency Department staff rarely took up her offer for short-term placements (even a few hours duration) working in the ASET unit, and training courses 'focused on triage, cardiac management, or new equipment that is around ... no-one wants to do training in aged care'.
- Management, especially of generic wards or services, where older people are often referred to as 'bed blockers', and the focus is on moving them on or out as soon as possible, and where staff do not feel supported when they seek to access dementia training.
- System issues, involving senior management in health and government, where the numbers of older people accessing health services are considered a 'problem', and the development of programs designed to prevent 'access block' are facilitated.

The Office for an Ageing Australia in the Department of Health and Ageing, and the Office for the Aged in DADHC have both undertaken initiatives in recent years to combat negative community perceptions of older people and people with dementia. More specific groups have also been targeted effectively in assisting specific community groups and/or services to develop better relationships with marginalised groups. Examples include the mental health project undertaken with hairdressers, "More than a hairdresser – improve your communication skills" (Hunter Institute of Mental Health (Web-site: <http://www.himh.org.au/site/index.cfm?display=34779>) and the training program by the Centre for Education and Research on Ageing (CERA) at Gosford City Council (Web-site: [http://www.cera.usyd.edu.au/resources\\_other\\_gosford.html](http://www.cera.usyd.edu.au/resources_other_gosford.html)). These may provide useful models for combating ageism and negative stereotypes of people with dementia within the broader community, as well as the health and care services.

One stakeholder with significant expertise in working with older people from CALD backgrounds suggested that all health and aged care services undergo cultural competency training, to assist them better target and support people from CALD backgrounds. This is particularly important given the fact that the majority of older people from CALD backgrounds access mainstream health and care services, rather than ethno-specific services, which tend only to be available to a handful of language groups. There is a significant need for additional resources to assist with capacity building in other major community groups, such as Arabic, Khmer etc. to assist them to better manage and support their community in culturally appropriate ways. This was particularly important given the cultural preference to stay living in the community, the culture of 'duty of care' for their elders in many communities, and the limited alternatives for culturally appropriate residential care.

Similarly, staff working with indigenous populations will need to understand the different aetiology and pathology of dementia amongst these communities, and the impact of the general health, lifestyle and social circumstances which place these communities at higher risk of dementia and complicating conditions.

A small number of stakeholders raised the importance of cognitive capacity assessment, particularly for lawyers involved in drawing up legal and financial matters. One respondent noted

that a cognitive capacity assessment underpins much clinical work, including duty of care issues, guardianship and placement decisions, as well as BPSD. The NSW Attorney General's Department recently issued its Capacity Toolkit, a guide to assessing a person's capacity to make legal, medical, financial and personal decisions. This was developed in response to requests from a range of lawyers, medical professionals, health workers, advocates and carers. There is potential for this to form the basis of a training program which could be widely disseminated, or incorporated into existing programs available to these key groups.

### 5.3.3 How should training be delivered?

This scoping study has identified a broad range of available formal training and education opportunities, and the list is by no means exhaustive. However, as the survey respondents have noted, accessing this training continues to be problematic for particular groups of health professionals and care providers. Some of the barriers to training have been discussed above in Section 3.5 of this report. These include workforce pressures, budgetary constraints, and a lack of management support.

Key strategies to enhance the uptake and spread of dementia education and training have been suggested by our respondents, and from our understanding of the literature.

One of the major strategies would be to have funding specifically available to back-fill staff members who are attending training courses in dementia. This is especially important for those in rural and remote areas, who may have to travel some distances to access education, the cost of which is borne not only by the staff member themselves (in terms of travel and accommodation) but also by the care recipients, who may not have anyone to provide the service in their absence. A few respondents suggested a 'flying squad' of trained nurses be developed to take over from staff to allow staff to attend training.

There are clear opportunities to better utilise flexible delivery strategies, such as Telehealth, e-learning and multi-modal distribution to target staff members who wish to undertake dementia training, but who may have limited access due to workforce pressures and cost constraints associated with attending off-site education. While a number of respondents commented on the number of self-learning/e-learning packages which had been developed in recent times, they also noted that their availability was not necessarily widely known. The creation and promotion of a web-site which brings together all the professional development and training activities would assist in raising the profile of these resources, as well as enhance the uptake of flexible learning opportunities.

Fundamental to the development of future education and training initiatives is the importance of identifying, utilising and supporting appropriate personnel already working within the health system. This is already evident through the current focus on in-service as the dominant vehicle for dementia training in acute hospitals, as specialist staff such as clinical nurse consultants (CNCs) respond to staff requests for assistance with management of particular aspects of care of a person with dementia. Case reviews and case conference are other important mechanisms for training and professional development. Established clinicians usually have significant experience working in a multidisciplinary context and with a range of audiences, and have the potential to contribute greatly to knowledge transfer and modelling to other health professionals. There are a number of benefits in using existing expertise which is already within the health system. These include raising the profile of existing specialists, clinicians and service providers; improving networking opportunities between staff, and across health service and program boundaries; validating those currently working in the field who have often worked in a context which has not valued their expertise; and opening up the development opportunities and career pathways for health professionals which would not otherwise have been available.

There are clear commonalities of information which cross professional and program boundaries and this provides an opportunity for the promotion of interdisciplinary professional development and training. An articulation of educational elements which comprise core/basic information, discipline-specific and specialist information could be a useful mechanism to encourage this interdisciplinary approach to dementia education.

Curriculum development, particularly with undergraduate courses for health professionals is critical. Additional focus needs to be given to caring for older people, people with dementia and their carers. This would assist in combating ageism and negative stereotypes regarding people with dementia, and reinforce the message that dementia is core business for the health and care systems. The Eastern Australia Dementia Training Study Centre (EADTSC) includes the objective of adding greater depth to the undergraduate curriculum in the area of aged care and dementia, as well as encouraging aged care/older adult placements, and facilitating clinical workshops and guest lectures. One framework for changing a profession's academic curriculum to include a focus on older people is presented by PSIGE – Psychology Specialists Working with Older People which is part of the British Psychological Society (see <http://www.psige.org/psige-pdfs/PSIGE%20BPS%20Nov%202006%20Good%20Practice%20Guidelines%20Training%20Providers.pdf>).

There is also potential for professional registration boards located within NSW Health to assist in clarifying these elements, and for requiring University and Vocational Education courses to include these elements in curricula which would lead to relevant professional registration.

Additional suggestions regarding professional training included:

- Tailoring training for the appropriate setting (community, residential care and acute);
- Developing training resources for the management of challenging behaviours;
- Conducting sessions over a two day period so staff can come in and out of the training session, and are provided with reflective opportunities;
- Ensuring that staff members have adequate access to computers and the internet to ensure they are in a position to take up the training available, and access the most up to date information regarding care and treatment options.

## 6 Recommendations

This scoping study has provided an up-to-date and independent assessment of the current efforts in dementia education and training in NSW. It has examined training models and identified a number of gaps in dementia training for health professionals and care workers in NSW.

The recommendations arising from this study are set out to address three funding levels:

- Short-term – priorities for one-off funding under the NSW Dementia Health Action Plan;
- Medium-term – opportunities for training should recurrent funding be available; and,
- Longer-term – systemic changes which could be undertaken to make dementia training more accessible and integrated within education and training programs for health professions, community care providers, and for the community in general.

### **Short-term recommendations:**

1. **Create a web-site which brings together all the professional development and training activities being undertaken in this State.** This site would build on the work of the National Ageing Research Institute in developing a *Dementia Resource Guide* (Web-site: <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>) for the Federal Government and would be specifically designed for health professionals and focus on self-learning packages. This initiative must include some funds to promote the web-site.
2. **Adopt a flexible approach to funding dementia training.** This should include funding for relief/backfill staff, as well as funding for training costs, travel and accommodation.
3. **Design a series of in-service training modules which are multidisciplinary in nature, addressing the following areas: preventing and managing challenging behaviour; communication; cognitive screening; and carers as partners.** NSW Health has a number of resources already developed which could easily be repackaged into in-service modules, such as *The Guidelines for working with people with challenging behaviours in residential aged care facilities* (NSW Health, 2006) and *the Care of Patients with Dementia in General Practice – Guidelines* (NSW Health, 2003a), and the “P3 Prevent, Plan and Protect” course run in the Illawarra. This is similar to the work done on the *Training Manual on Suicide Prevention for Older People* (NSW Health, 2003b).
4. **Develop an education and support network for existing dementia health professionals.** This builds on the dementia CNC network currently across NSW, Behavioural Assessment and Intervention Services (BASIS) and Dementia Behaviour Management Advisory Services (DBMAS). There are clear opportunities for widening and evolving the consultation and liaison role of these groups to support professional development and networking. It is also important to note that NSW Health has created a network of 9 CNCs in dementia in acute care across NSW (NSW Health, 2007).
5. **Provide training in effective case conferencing for team leaders, so case reviews and family meetings can be used as education opportunities for staff and families.** Using a case review and planning process as a way into care services and sites, is being used by Aged Care Services in Emergency Teams (ASET) and Acute to Aged Related Care Services (AARCS). It has also been identified as critical for the effective care and management of people from a CALD background. This approach, along with the work of ACATs, can be built upon for professional development and education purposes.

6. **Design and undertake a dementia awareness program for support service workers in NSW Health (using Table 1 as a guide for whom to target).** It is noted that developing Dementia Training for Ambulance Workers is underway as part of the Australian Government's *Dementia A National Health Priority Initiative* (see LAMA Consortium, 2007). Resources also need to be use to given to promote acceptable language when referring to people with dementia, so we are no longer hearing about "demented patients"
7. **Provide Health Care Interpreters with dementia training based on previous training delivered, and which targets permanent as well as sessional workers.** These individuals are often the interface between people of CALD backgrounds and health professionals, and potentially HACC services in the future.

***Medium-term recommendations:***

8. **Develop standards for dementia care, implementation strategies and key performance indicators to underpin the Dementia Service Planning Frameworks being developed under Priority 1 of the NSW Dementia Plan.** For example, this could include protocols within all EDs that all people 70+ who present are seen by an Aged care CNC or equivalent; and that no-one over this age is discharged between 8pm and 8am. These would reinforce the message that dementia is core business for health and community services.
9. **Require the Dementia Service Planning Frameworks to include an education and training agenda.** This would address needs and gaps identified through service planning, and allocate appropriate resources. This would include conducting surveys and audits into educational activities by health services in AHS (e.g. one such survey has been carried out in SESIAHS).
10. **Develop an integrated model of care for people with dementia admitted to emergency and acute care services.** This should include a person centred care philosophy emphasising a multi-disciplinary approach with time for critical reflection to drive practice improvement.
11. **Consideration should be given to requiring mandatory training in the dementia and delirium for all health professionals.** This would include health professionals working in the acute care sector, either as part of their induction training, and/or annual training requirements.
12. **Place a greater emphasis on dementia training in resident/junior medical officer training.** This would include discussing and addressing this issue with the NSW Institute of Medical Education and Training in their Hospital Skills Training program.
13. **Develop carer's online training/e-learning packages in collaboration with Commonwealth Carer Respite Centres (CCRC) and the Dementia Collaborative Research Centres.** Any training package should be heavily promoted to ensure maximum awareness within the general community of their availability.
14. **Extension of the training resources developed for ATSI and CALD communities as part of previous NSW and Australian Government dementia strategies to include more community groups.** This activity should be conducted as part of capacity building within these communities to enable them to better care for their members with dementia.

- 15. Develop a mentorship and supervision program to support new graduates and those health professionals moving into the aged care and community sectors.** This would utilise role modelling to help new workers develop and adapt their clinical practice. The key issues being: “motivation, knowledge, support and attitudes”.

***Longer term recommendations:***

- 16. Promote the enhancement of undergraduate curriculum for health professionals to include more focus on caring for older people, people with dementia and their carers.** This would assist in combating ageism and negative stereotypes regarding people with dementia, and reinforce the message that dementia is core business for the health and care systems.
- 17. Work with the relevant health professional registration boards, such as the Nursing and Midwives Board NSW to require greater focus on aged care and dementia within the curriculum of undergraduate courses leading to registration.** This would also assist in the promotion of dementia care as desirable and valued career option.
- 18. Review and redevelopment of dementia education available to be able to build into a professionally recognised or accredited framework.** Build better linkages between dementia training and professional development by rewarding staff who undertake online, self-directed learning packages.
- 19. Encourage other agencies to develop strategies to raise awareness of dementia.** This could include agencies such as DADHC and the Office for an Ageing Australia in the Department of Health and Ageing to enhance previous strategies adopted to raise awareness within the general community about dementia, and to combat ageism, negative stereotypes about people with dementia, as well as promoting respect for older people.

In conclusion, we would note that this work has provided an up-to-date and independent assessment of the current training and professional development landscape in NSW. We have sought to provide clear recommendations to the Department to move forward in this area - in terms of funding of effective, targeted and high value training projects.

In considering the recommendations arising from this study, we encourage the Department to establish a steering committee of relevant stakeholders who could provide advice regarding the development of a rigorous evaluation framework. Sufficient funds should also be provided to promote any tools or training packages that have been developed, or which will be developed arising from this project, especially for those which are internet based.

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## Attachment 1

### Organisations / health professional groups who participated in the scoping project

#### Peak Organisations

- Carers NSW
- Aged Care Association Australia NSW
- Alzheimer's Australia NSW
- Aged and Community Services Australia (NSW & ACT)

#### Training Providers

- Faculty of Nursing, Midwifery and Health, University of Technology, Sydney
- Rural Health Education Foundation
- Eastern Australia Dementia Training and Study Centre, University of Wollongong
- TAFE (Nowra)
- Dementia Services Development Centre, The Hammond Care Group
- School of Nursing and Midwifery, University of Newcastle

#### Area Health Services (Metropolitan)

- South Eastern Sydney/Illawarra AHS
- Northern Sydney/Central Coast AHS

#### Area Health Services (Rural)

- Greater Southern AHS
- Hunter/New England AHS

#### Health Professional Groups

- Royal Australian College of General Practitioners, NSW and ACT Faculty
- Aged Care Integration, Inter-government & Funding Strategies Branch, NSW Dept of Health
- Palliative Care, Sydney West AHS
- Occupation Therapy, South Eastern Sydney/Illawarra AHS
- Australia & NZ Society for Geriatric Medicine
- Psycho-geriatric Nursing, North Coast AHS
- Disability Advisory Service, Office of the Protective Commissioner
- Specialist Mental Health Service for Older People (SMHSOP), Centre for Mental Health
- Neuropsychology, Sydney South West AHS
- Ethnic Aged Health, Sydney South West AHS
- Aboriginal Health Liaison Officer, NSW Health
- Aged Care Services in Emergency Team, South Eastern Sydney/Illawarra AHS

#### Other

- Dept. Ageing, Disability & Home Care (DADHC)

## Attachment 2

### Scoping Survey

# Dementia Training for Health Professionals Scoping Survey



#### Introduction

The Centre for Health Service Development (CHSD), at the University of Wollongong, has been contracted by NSW Health to undertake a scoping study of dementia training within NSW. As part of this work, a short nine (9) question telephone survey of relevant organisations in NSW is being conducted. We seek to interview a range of individuals from training provider organisations, carer organisations, professional groups and Area Health Services.

This survey asks about your views about dementia training within NSW. The purpose of this scoping survey is to:

- Inform the Department of the current status of dementia specific education and training for health professionals in NSW; and
- Guide the Department where to direct one off training funds available under the NSW Dementia Action Plan 2007 – 2009 and where any future available investment would be the most effective.

This information provided by individuals, as representatives of their organisations, will be kept confidential, and only grouped responses and non-identifying data will be used in the report. The intention is to add to our knowledge about dementia training in NSW; not to make comparisons between organisations or health services, but to inform policy and service development.

#### Instructions

Attached is a schema of the *Dementia Patient Journey*, developed by NSW Health, which depicts the range of workforce groups and services that people with dementia and their carers may access and interact with along the dementia trajectory. Please take some time to review the *Dementia Patient Journey*, as it provides the framework for the interview.

When answering the interview questions we would like your perspectives on the training needs of health professionals working in general health or community care services (e.g. nurses, general practitioners) as well as health professionals working in dementia specific or specialist services (e.g. dementia CNCs, psychogeriatricians).

Finally, if you have any written material about dementia training and dementia training programs, which may be of use to this project, please send it to:

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## List of Questions

*Before we start the interview, could you please describe the dementia training activities undertaken by your organisation, or which dementia training activities your organisation has participated in, during the past 12 months. Please include information about the topics covered, the goal(s) of training, its delivery mode (eg. case conference or lecture) and frequency (eg. monthly).*

1. In terms of priority, which health professionals should be targeted for dementia training?
2. In terms of providing high quality dementia care, what are the priority training needs?
3. Are there prerequisites for dementia training, such as addressing attitudes towards older people and willingness to identify and address individual care needs?
4. What are the current dementia education and training opportunities available? (For example: the training initiatives under Dementia as a National Health Priority, like the Eastern Australia Dementia Study Centre; training provided through Alzheimer's Australia NSW; other specific dementia training that can be accessed at state and/or AHS level like the acute care training module or the behavioural disturbance module)
5. What are the current barriers to training (eg. access for rural and remote staff, workforce pressures)?
6. Where is training currently targeted – TAFE, University (undergraduate/postgraduate) or In-Service training?
7. What are the perceived gaps in dementia training in NSW? What topics are not covered in dementia training (For example: Do training packages cover some of these issues: people with younger onset dementia or people with intellectual disabilities as well as dementia; practical and safe ways to avoid escalating distress; and the assessment and management of pain for people with dementia?)
8. Who does not received adequate dementia training?
9. If funds were available, how should the funding be allocated to achieve maximum benefit in terms of value for money, and to provide maximum benefit in terms of improved dementia patient care? (Including one-off investments in training, as well as training programs based on recurrent funding models)

*Are you willing to be contacted again to discuss dementia training issues?*