



“KEEPING THINGS FLOWING”

FINDINGS FROM PARTICIPATORY ACTION RESEARCH

INVESTIGATING THE PRACTICE MODEL

FOR A RURAL DEMENTIA OUTREACH SERVICE

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**Atosha Clancy
Team Leader/Social Worker
Dementia Outreach Service
Northern NSW Local Health District
PO Box 523 Ballina Tel: 6620 6283
atosha.clancy@ncahs.health.nsw.gov.au**

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The Team, Dementia Outreach Service, NNSW LHD

Professor Lesley Barclay, University Centre for Rural Health, Lismore

Dr Emma Webster, Health Education & Training Institute: Rural and Remote Portfolio

Mr David Schmidt, Health Education & Training Institute: Rural and Remote Portfolio

Dr Judy Singer, University Centre for Rural Health, Lismore

Ms Grace Burgess, Colleague/Backfill, NNSW LHD

Ms Lisa Diett, Community Health Manager Ballina, NNSW LHD

Lisa Beasley, Manager Community and Allied Health, Richmond Network, NNSW LHD

Ms Cathie Nilon, Librarian, Lismore Base Hospital, NNSW LHD

The participants of the focus groups

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ABBREVIATIONS

DOS	Dementia Outreach Service
ACAT	Aged Care Assessment Team

ABSTRACT

BACKGROUND

Currently 70% of the 320,000 Australians with dementia live in the community. The number of people with dementia is projected to increase by 39% this decade. It is timely therefore to investigate models of service delivery that provide support to this important target group. There is a dearth of literature about effective models that enable the advances in intervention and management to be delivered to people living at home. The author of this paper is a social worker and team leader of a rural dementia outreach service, who has undertaken this research project supported by NSW Health.

GOAL

In a time of increasing population pressure and national policy changes the far north coast Dementia Outreach Service needs to continually review the nature and extent of its core business. With increasing demand for service stretching the Dementia Outreach Service's finite resources, it also has to review whether there are better ways of delivering service. To inform such reviews and establish good practice, the Service needs to articulate its practice model and identify the knowledge and skill base on which that model sits. The research goal therefore is to investigate the practice model of this rural dementia outreach service to enable the Service to make informed decisions about how it responds to service constraints.

METHODOLOGY

Participatory action research methodology has enabled staff, community agencies and experts to contribute to the study and allowed the researcher to be a participant in the research. Data were collected through four focus groups and service records. A review of literature, policy, funding, demography and workforce contextualised the study.

RESULTS

Data analysis has been an iterative process with thematic analysis from the preceding group feeding back into subsequent groups. The findings are in four areas. The first area identifies the influences that the broader context has had on the Service, including population increase, policy changes and challenges in the health sector. The second area describes a practice model which identifies target groups, theoretical foundations, pillars of practice, core activities and the "enablers". The third area explores the knowledge and skill base of the service and the highlights the importance of clinical expertise and the multidisciplinary team. The fourth area lists the shortfalls of the Service.

CONCLUSION

A practice model is described for a clinically-based, community-positioned, multidisciplinary dementia outreach service in the Australian rural context. Multiple external determinants are identified that have shaped the development of the model. Flexibility and responsiveness are key for building a cohesive sector response, for maintaining person-centred care, and for "*keeping things flowing*" for people living with dementia.

KEYWORDS *dementia outreach, practice model, multidisciplinary team, sector cohesion, clinical expertise*

THE GROWING PROBLEM

Dementia already influences the health, community care and aged care sectors. The impact of dementia will grow, with population projections indicating a tripling in number of people with dementia to 900,000 by 2050. In addition to the numbers, the complexity of this group is increasing as people are being diagnosed earlier, with a wider range of cognitive disorders and at younger ages. Whilst infrastructure reforms are required at the national and state level to respond to these increases, it is at the local level that services are delivered to people living with dementia. Sound service delivery models are needed to ensure that existing clinical expertise and knowledge is being delivered efficiently to people living in the community. This study examines one rural dementia outreach service on the far north coast of NSW that has been operating for more than a decade, providing service to people living at home with dementia and to the community sector that supports them.

THE STUDY

The study invited people who were familiar with different aspects of the Dementia Outreach Service to contribute to discussions in focus groups. The groups comprised 21 staff from the Service, the not-for-profit community dementia sector, and dementia and discipline experts.

FINDINGS

The findings are grouped into four areas.

Finding 1

For more than ten years, the Dementia Outreach Service has been growing its model of service and delivering its core business. It has been changing in response to the context in which it operates, and the absence of prescribed models has allowed the Service to respond to local need with flexibility. As lead agency in the far north coast Dementia Pathways Forum it has had a pivotal role in building a cohesive dementia service sector. However the increasing pressure from population growth, changes in policy and funding, and challenges from within the health system, have stretched resources to the limit. The Service struggles to meet growing demand, fill gaps in service, maintain clinical expertise and support the community service sector.

Finding 2

A practice model for how the Service does business was clarified by this study. The target groups are people living at home with dementia and the community service sector. The theoretical foundations that underpin the model are: knowledge about the nature of the illness of dementia, and person-centred care. The practice model sits on five pillars: early intervention, outreach, clinical expertise, the multidisciplinary team and a cohesive sector response. From that solid base, the Service engages in seven core activities: it leads, it responds, it links, it innovates, it builds, it consults and it manages. The model is sustained by enabling factors, both process enablers and people enablers.

Finding 3

This enquiry into the knowledge, skill and discipline base of the Service has highlighted two key points. Firstly, the Service's clinical expertise and the multidisciplinary team are highly valued by the staff, the community service sector and the dementia experts. Secondly, both are viewed as essential components for providing an integrated and cohesive service response to people living with dementia. This is because the Service links the dementia experts (such as geriatrician and clinical geropsychologist) to their clients; brings clinical support to the community service sector; and provides clinical care to carers and people with dementia through individual interventions and group programs.

Finding 4

The identified shortfalls of the Service were related to resource limitations and system constraints. The shortfalls included inequitable access, particularly for people who cannot obtain a diagnosis; an inappropriate model for Aboriginal people; withdrawal of service too early in the progress of the disease; overlaps and gaps with other services and a lack of focus on community awareness-raising.

IMPLICATIONS

The value of this study is that it presents a practice model that has been informed by clinical and community staff who specialise in working with people with dementia who live at home. This study makes recommendations that are timely and relevant to the infrastructure reforms taking place in the aged care workforce and service system. It recommends the inclusion clinical expertise and multidisciplinary teams in community outreach services, and the adoption of a bio-psycho-social approach for the management of people with dementia. It points to the need for further research into the cost and benefit of such community outreach models, and recommends the development of culturally appropriate models for Aboriginal people. For service delivery at the local level, the study supports the building of a cohesive sector response, and makes recommendations for improving that response on the far north coast of NSW. For the Service being studied, the articulation of the practice model provides a basis for making good decisions about the how the Service can best operate into the future. The study recommends that the Service make itself available as a research site for further studies into the cost and benefit of community outreach models for dementia care, for implementation of the inter-disciplinary competency framework for dementia, and for evaluating the effectiveness of the practice model on client outcomes. The findings and recommendations will be of use to policy makers, funding bodies, organisational planners, service providers and fellow clinicians.

INTRODUCTION

The purpose of this study was to investigate the practice model of a rural dementia outreach service. The subject of the study is the far north coast Dementia Outreach Service, henceforth called DOS or the Service throughout this report. The research is timely, given the current reforms occurring in aged and dementia care which have been brought about by demographic, policy and funding changes.

CONTEXT

POPULATION AND DEMOGRAPHICS

Dementia is a major health problem in Australia^(1, 2) and is predicted to become the leading cause of disability in Australia by 2016⁽²⁾. The number of people with dementia is projected to triple between 2011 (298,000) and 2050 (900,000),⁽³⁾ with the current decade to see the greatest growth (39%)⁽³⁾. It is estimated that of these people 8% will have younger onset dementia, meaning that they are under the age of 65⁽³⁾.

With an estimated 70% of people with dementia living in the community, around 200,000 Australians are caring for a person with dementia⁽³⁾. Roughly half of these carers are themselves aged 65 and over. The burden of caregiving for those caring for a person with dementia, when compared to other chronic conditions and disabilities, is particularly high and can impact the physical, mental and emotional well-being of the carer⁽³⁾.

Regional Australia is ageing faster than the cities⁽⁴⁾. Tweed State Electoral Division had NSW's highest projected prevalence of people with dementia in 2013 (1956) and is projected to still have the highest number in 2050 (7451)⁽⁴⁾. This increase of 281% in Tweed is closely followed by increases for the three other Divisions that comprise the far north coast: Ballina 267%; Clarence 255% and Lismore 246%⁽⁴⁾. These numbers are alarming.

WORKFORCE

The ageing of the population and the projected numbers of people with dementia has implications for the Australian workforce. These impacts are already being felt as the first of the "baby boomers" (those born between 1946 and 1965) turned 65 years of age in 2011.⁽⁵⁾ Their ageing increases the total number of aged persons whilst decreasing the proportion of working Australians. By 2050, 26% of the population is projected to be over the age of 65⁽⁵⁾. Their ageing will have a greater impact in some rural and coastal areas, such as the far north coast, as many retirees move to these areas. This trend will increase service demands in rural areas which already have a high proportion of aged persons and face workforce shortages⁽⁵⁾.

The workforce that serves people with dementia is decreasing. The number in the unpaid workforce, from which family carers come, is expected to decline⁽⁵⁾. The formal workforce comprises health and aged care workers. This workforce is already facing shortages in nursing⁽⁵⁾, in allied health⁽⁶⁾ and medical practitioners, who are disproportionately placed in metropolitan areas⁽⁵⁾. Health workforce shortages are compounded by a move to lower average working hours⁽⁵⁾.

In addition to shortages, there are other challenges facing the health workforce in relation to aged care⁽⁷⁾. Traditionally, work allocation is determined by discipline; and within disciplines there is increasing specialisation. This leaves the health workforce lacking the flexibility to embrace emerging service models; for example, it lacks support, supervision and training for workers providing the assistant, support and supplementary workforce⁽⁷⁾. Australian workforce reforms use a competency lens, rather than discipline, to decide who does what by identifying actions and responsibilities in each competency⁽⁷⁾. A competency framework has been developed for dementia care nursing⁽⁸⁾ and an inter-disciplinary framework currently under development in NSW will contribute to the redesign of the dementia workforce⁽⁹⁾.

THE RESPONSE OF GOVERNMENT

Dementia poses a substantial challenge to health, aged care and social policy⁽³⁾. In response, governments at both the Federal and State level have developed plans for action on dementia^(1, 10). The Commonwealth has initiated major reforms to the aged care system and the health workforce to address the challenges of the changing demographics^(2, 7). These are still in the early stages of implementation. A key building block of the aged care reforms was the shift of program and funding responsibility for older Australians from the States to the Commonwealth Government in 2012⁽¹¹⁾.

NSW Dementia Advisory Services

Three Dementia Advisory Services were piloted under the first NSW action plan including one in the far north coast which is the subject of this study. The program was expanded to become 24 Dementia Advisory Services across NSW⁽¹²⁾. A key finding of the 2008 evaluation of these services⁽¹²⁾ was that they contributed significantly to sector development, sector planning and direct service provision for people with dementia. Of significance to this study, it identified that there was no common service model amongst the 24 services⁽¹²⁾ and each developed in response to context and auspice.

The FNC Response

Following the establishment of the Dementia Outreach Service in 2002, the Far North Coast Dementia Pathways Forum was formed and has continued to meet bi-monthly. Its membership is drawn from government and not-for-profit providers that have a focus on community dementia care. Its purpose is to share information, ideas and innovations in the provision of dementia care. The Forum has developed two action plans for the far north coast covering the years 2008-2011 and 2012-2015. The DOS is the lead agency in this forum, providing both chair and secretariat roles.

THE LITERATURE

Literature search:

Four searches were conducted in November 2011 using OVID. Search terms for the four searches included the following: (1) Care, centred, dementia, person, person-centred care (2) Dementia + person-centred care + Caregivers, community networks, delivery of health care, dementia, loneliness, outcome and process assessment (health care), patient-centred care, primary health care, program development, program evaluation, quality of life, social alienation, social isolation, social support (3) Care, dementia, models, models of care (4) Dementia, and outreach. Searches were limited to the years 2001 to 2011. To limit the search to community care, the terms, residential aged care, nursing home, aged and care homes were excluded. The initial search netted 60 articles. Additional articles were reviewed, chosen on the basis that they had been written by the same author(s), or that they were cited in the bibliography of the original articles. As data analysis was an iterative process further academic literature was sourced throughout the research process. The data collection phase also entailed an extensive review of the “grey” literature to capture the many variables impacting on the Dementia Outreach Service, including government policies, service evaluations and government reports. A template for analysing the literature was developed.

Literature Review:

The review identified four themes within the literature.

Theme 1: Person-centred care is the dominant philosophy in dementia care⁽¹³⁾ and has become synonymous with quality care⁽¹⁴⁾. What constitutes the practices of person-centred care is unclear⁽¹⁴⁾. It is seen as care that operates from a value base⁽¹⁵⁾ and “is a multidisciplinary concept describing care that is based on and includes people’s subjective experience of illness” (Edvardsson et al 2010 p2612). As person-centred care focuses on the experience of the person with dementia, it is often used as a lens through which researchers look to evaluate dementia services; for example, memory clinics⁽¹⁶⁾, multi-component group therapy to preserve cognitive function⁽¹⁷⁾ and end-of-life care⁽¹⁸⁾. Person-centred care requires the philosophy and practice to be embedded in organisational culture; and conversely, it requires staff to share that philosophy and implement its practices⁽¹⁵⁾. Recent notions about “welcoming family”⁽¹⁴⁾ have recognised the importance of family and significant others in person-centred care, and validated constructive relationships between workers and family carers.

Theme 2: The Carer: Family carers play a critical role in sustaining people to live at home^(19, 20), and the impact of caring on the health and well-being of the carer is significant⁽¹⁹⁾. Hence there is a need to focus on carers, and the benefits of carer programs are well documented⁽²¹⁾ both for the sake of the carer, and because carer burden impacts negatively on the person receiving care. Carer programs include both educational programs⁽²²⁻²⁵⁾ and psycho-educational group programs⁽²⁶⁾.

Theme 3: Models of community care for people with dementia: Case management has been found to be suitable for complex conditions, such as people with dementia⁽²⁰⁾. Studies have found that the presence of a multi-disciplinary team improves case management initiatives; and that this is further strengthened when linked to medical decision-making⁽²⁰⁾. Successful case management offers

psychosocial support as well as practical care, particularly when provided both to client and carer⁽²⁷⁾. The position of the case manager in the provider network, their willingness to cooperate with others and their linking of carers to services are identified success factors⁽²⁰⁾. A different model of community care described in the literature was that of a nurse-led dementia outreach team providing interventions for people within residential aged care facilities. The intervention involved hands-on support for the person in care and education and modelling for the staff⁽²⁸⁾. This single service study highlighted that enthusiastic grassroots services have the potential to influence health care policy and practice⁽²⁸⁾.

Theme 4: Integrated and innovative care: The current health infrastructure is inadequate for the looming increase in the number of people worldwide with dementia⁽²⁹⁾. Fragmentation of services is a worldwide problem^(20, 29). With the increasing pressure of numbers and necessary cost containment, integration to provide seamless care is advocated⁽²⁹⁾. The development of innovative models of care could prepare the health and community care system to respond through a “more integrated and comprehensive approach to care” (Callaghan et al 2009 p368). Whilst innovative models may be effective in implementing the available knowledge, they will “require system-level changes . . . beyond the reach of the typical small primary care practice” (Callaghan et al 2009 p372). The trialling of “specialty dementia clinics that provide comprehensive and coordinated care” was suggested (Callaghan et al 2009 p372).

RESEARCH QUESTION

This research project seeks to answer the question: What is the practice model of the Dementia Outreach Service? To answer this question, the study explored two further questions: What are the external factors that influence the model? What theory, knowledge and skill base underpin DOS?

STUDY DESIGN

Methodology

Participatory action research^(30, 31) was chosen as the methodology of this investigation as it enabled staff, community agencies and experts to contribute to the study and allowed the researcher to be a participant in the research. A review of literature, policy, funding, demography and workforce contextualised the study.

Setting

This study took place at the Dementia Outreach Service, a 10-year old, government-funded service that sits within the Northern NSW Local Health District. DOS provides an outreach service to people diagnosed with early stage dementia living at home and their families throughout the far north coast of NSW. The Service is funded for 4.4 positions and staff have allied health or nursing qualifications. Their outreach role involves visiting people in their homes and conducting group programs in the community.

Ethics

Approval was given by the North Coast Area Health Service Human Research Ethics committee on 6th December 2011, reference NCAHS HREC No LNR020.

Researcher

The researcher is a social worker who has been team leader of the service since 2005, is chair of the Far North Coast Dementia Pathways Forum, and has no prior experience in research. The researcher

believed that DOS was providing a high quality service with skilled workers. An independent facilitator was therefore included in the study design to reduce real and perceived bias by the researcher and to increase transparency.

Action Research Team

All five staff of DOS accepted the invitation to be part of an action research team^(30, 31) which was formed to provide input to the research project and be involved in refashioning the Service. The team reduced to four following the resignation of one member (who has not been replaced) half way through the study. The action research team met following the monthly team meetings and eight of those meetings were minuted. The action research team was involved in tasks such as developing the criteria for sampling, discussing the issues arising from the data and service improvement. With a high level of team engagement in the project there were many informal discussions outside of the formal meetings.

Sampling

Data were collected from four focus groups. Purposive sampling was chosen to ensure that participants were those that could provide valuable data. Sampling criteria ensured representation from across the geographic area, service types and disciplines. For inclusion, participants representing the community services needed to be in professional contact with the DOS for more than one year, ensuring that they had knowledge of the service. Hence these participants all knew the researcher. Letters of invitation were posted; those who declined stated that focus group dates clashed with work commitments.

Group 1 comprised all staff of the service, including the researcher (n=6).

Group 2 comprised representatives of the community services providers in dementia care (Invited n=10; participated n=7). These services will be referred to as the community partners in this report.

Group 3 comprised people with expertise in dementia or in a health discipline; all but one had expertise in both. Disciplines included were nursing, social work, occupational therapy, psychology and medicine. Another member was included because of experience in policy and funding of dementia services. (Invited n=10; participated n=8).

Group 4 comprised participants from all groups. All were invited back; several were unable to attend due to work commitments (from Group 1 n= 4; from Group 2 n=2; from Group 3 n=6; total n=12).

Whilst every effort was made to protect the privacy of participants (including not providing a detailed list of their qualifications, ages and gender for this report), participants were made aware in giving consent to participate that others may guess or assume their identity, given the rural location in which the study was conducted. Each participant has been given a unique code, numbered 10 to 30. No quotes from the researcher are included.

Data Collection

The four focus groups from which data were collected were conducted in a regional town chosen because of its central location. Questions for each group were decided by the researcher and facilitator. Each group built on the knowledge gained from prior groups. The questions for the two-hour groups are included in Appendix 1. Data was also sourced from Service records, from the action research team and from the "grey" literature about policy, funding, demography and workforce.

Focus Group Facilitation

An independent facilitator with an academic background in qualitative research facilitated all focus groups. This allowed the researcher to be a participant in the first group and a participant observer in all others. As the facilitator had no prior knowledge of the Service nor was known to any participants, potential and perceived bias was reduced. The facilitator met with the researcher before and after each focus group to develop the questions and to debrief.

Data Analysis

Audio recordings were made of all focus groups and transcribed by the researcher. Field notes were taken during the groups and at post-group debriefing with the facilitator. Action research team meetings were minuted. As the analysis was an iterative process, data from each focus group informed questions for subsequent groups. Transcriptions and notes were read, re-read, 'cut and pasted' and coded into themes that emerged from the data. Themes were developed into working models which changed as new data were added. Data from Service records and the action research team clarified information; and the "grey" literature contextualised the study.

Data Checking

The researcher presented a synthesis of the findings to the fourth focus group for the purpose of validating the data; subsequent discussion added clarity and provided additional explanatory and confirmatory data.

RESULTS/FINDINGS

FINDING 1: CONTEXT HAS A SIGNIFICANT IMPACT ON THE SERVICE

Though only a small rural service, the context in which the Service operates and the nationwide changes occurring in the aged care sector have had many direct impacts on DOS. These are outlined below.

Population increase and demographic changes

The population increases and changing demography, coupled with the implementation of more than a decade of government action plans on dementia, has led to a change in referral patterns. DOS had a 22% increase in referrals in the last financial year. (DOS CMSS Filemaker database, accessed 7/3/13)

"We are moving to much more early diagnostic models which 10, 15 years ago wasn't an issue".
(21)

The characteristics of the client group are changing. In recent years 7-10% of referrals have been for people with dementia under the age of 65. (DOS CMSS Filemaker database, accessed 7/3/13)

"The referral patterns have changed from where they were almost exclusively people who were elderly with Alzheimer's disease to now encompassing a wide range of people in variable age groups from 50 through to 80 . . . the needs of people in the younger age group are different and much more complex in many ways . . . it means that it is very difficult to handle the patient load because of the diversity of people that are presenting to the service now". (20)

Staying in front of these shifts in client demographic and volume requires a matching shift in clinical knowledge and service models.

"It is not a single identity of dementia; it's a multi-factorial bio-psycho-social problem and for that reason we can't have a fixed model of care" (20)

Workforce Challenges

Workforce ageing: The age range of DOS staff (early forties to late fifties) and of the expert colleagues with whom they consult (over the age of sixty) mirrors the ageing health workforce. (Action research team meeting, 19 March 2012)

Community partners: Keeping the skills of the workforce up to date is a challenge for the community partners:

“The demographic that we are dealing with through DOS has had subtle changes over the years, which means that the training that was given to the service providers no longer replicates the type of people that referrals are coming through for. So the 10% of younger people for example are often very difficult for the services to manage because they haven’t got resources and they haven’t had the training to manage those people, and they don’t have the model of care” (20)

This leaves DOS with limited referral options, so the service holds on to cases longer. This not only increases caseloads but also adds stress on staff as the cases being held are often the most difficult ones. Compounding this, some community partners stated that they have come to rely on the Service’s clinical skills and its willingness to stretch to meet need, and hence have not invested in building the needed skills and capacity.

Funding Impacts

Shift in funding responsibilities between Commonwealth and State governments: The shift from State to Commonwealth funding for older Australians in 2012 has resulted in DOS losing its working relationship with the regional office of the state funding body. That relationship was effective because the funding body worked with DOS and the Dementia Pathways Forum to identify emerging need, and target growth funds to those areas and towns. The shift has led to a loss of voice with the funding body for DOS and the target group it supports.

“From a funding body point of view, to be able to sit at the Dementia Pathways Forum and listen was just the most valuable planning process and to then be able to target funds; and it really bothers me that that doesn’t happen with the Commonwealth anywhere; and I don’t know what the consequences of that are going to be.” (18)

Funding limitations on community partners to provide services for carers: With the exception of the (former) National Respite for Carers Program, most funding models classify the person with dementia as the client and not the carer. Yet dementia requires a comprehensive bio-psycho-social approach that includes carers and family. With the funding linked to the person with dementia, the capacity of community partners to provide service to carers is limited, even though they push the boundaries of funding agreements to include carers where possible.

“Are we doing the right thing by the carer by giving the service to the client and saying oh yes we must make sure we give you (the carer) your respite so you can go off and do something. We are not actually looking at the full extent of what the carer’s needs are . . .we don’t really attend to the carer’s real needs. (15)

This systemic limitation has resulted in DOS taking on the lion’s share of providing support and education for carers across the far north coast. And whilst a proportion of DOS funding has been specifically for carers, the need is greater than the allocation. This has given rise to dilemmas regarding service to carers. Some examples were discussed, such as: how much service is enough? Does the Service continue to support a carer who is in distress when the person they care for is no longer a client of the Service? How do staff balance the clinical needs of people with dementia with those of the carer in terms of resource allocation?

No prescribed model for the NSW Dementia Advisory Services has led to development of unique model

With no service model prescribed by the funding body, DOS developed its own.

“This particular service is unique . . . there is no replication of the service delivery model anywhere else in NSW . . . it has provided some flexibility to meet the local demographic needs . . .and the model has achieved some great innovative milestones along the way. So flexibility is helpful and the funders have allowed us to be flexible within that”. (28)

“The funding body tried to respond to the needs that were identified by the service; and because the funding body has to fund under service types, what that meant was that (DOS) didn’t just have case management as a model or social support as a model or information or counselling or education or carer support. It actually got funded for a whole range of things. And I think that’s the strength, it can do a whole range of things”. (18)

Health service challenges

With dementia posing a major challenge to the health service system, the auspicing of DOS by the local health service has influenced the development and operations of the service. These influences can be grouped into seven areas.

Positioning of DOS in health service:

The advantages and disadvantages of being positioned in a health service were discussed.

“There are certainly some advantages, like access to health professionals, client records . . . we have to look at some of the limitations in health because there is no other service in health that operates like DOS . . . and it’s sometimes a battle trying to convince people that this is a health-type service and (DOS) should be allowed to do things quite differently, because they are funded quite differently”. (16)

The health service was perceived as shifting to a reactive mode which is at odds with DOS’s proactive clinical and community role and was placing increasing stress on staff.

“If we are going to overcome the wave that is building up on us, we have to move to a proactive model. But health is moving DOS to a reactive model . . . and you’re not going to manage it on a reactive basis; you’re going to have to move to a proactive basis. Because if you don’t the wave will break over the top of you. And I think that dichotomy has caused a lot of grief in DOS over a lot of years”. (20)

Lack of community care model: The health service auspices several programs that are specifically funded for people with dementia. Locally this includes DOS, the Dementia Behaviour Management Advisory Service, the Dementia Community Nurse Consultant and Dementia Support for ACAT. Each program comes with funding that determines the target group and scope of the program. However, as programs are placed in a rural health service that lacks models of community care, it has led to the development of silos. The building of silos is exacerbated by the absence of a single management structure for aged care services.

“you really need to have a seamless service, and that’s the problem when you start adding new roles or going down another laneway; those services need to be consolidated and seamless and . . . I think it needs to be part of a holistic dementia service”. (28)

Care pathway for people with dementia: Comprehensive clinical guidelines and care pathways for people with dementia from diagnosis until death were published for the Australian context in 2008⁽³²⁾. Recognising that the journey of dementia spans many years, the document provides guidelines, practice tips and care pathways for the many workers who will be involved in the care of a person living in the community with dementia⁽³²⁾. The NSW Dementia Service Framework 2010-2015 proscribes a service pathway from dementia awareness to palliative care⁽¹⁰⁾. Several actions recommended in the framework involve the NSW Dementia Advisory Services and the NSW Ministry of Health. The policy work to implement the framework is currently being undertaken. Whilst this work may lead to a funded care pathway in the future, it is not currently provided by acute and community health services; there are service gaps along the care pathway. The two gaps of most concern to participants were diagnostic services and services for people with moderate to severe dementia living at home. These gaps have challenged DOS in two major ways. Firstly the service has extended beyond its core business of early

stage dementia to provide community memory clinics for the undiagnosed. The Service is currently withdrawing from memory clinics to focus on core business; yet the memory clinics provided an important pathway to diagnosis and were valued by clients, general practitioners and the geriatrician. Secondly DOS has maintained service to some people who have moved beyond the early stage of dementia as staff feel it would breach duty of care to withdraw service. This has created angst and pressure for staff.

The shortage, and the uneven distribution, of geriatricians: Geriatricians provide the greatest source of referral to DOS; so whilst a shortage of them keeps the referral rate down, the uneven distribution results in different referral patterns across the Tweed, Richmond and Clarence valleys. Hence the service response to people in the Richmond valley (who are likely to get diagnosed earlier due to better access to a geriatrician) will be more comprehensive and timely than to folk in the Clarence and Tweed Valleys who are more likely to be diagnosed later as there are no geriatricians based in either of those valleys.

“In our area one of our shortfalls is that we don’t have diagnostic services, we don’t have a geriatrician . . . so often we don’t have a diagnosis to be then able to refer onto DOS”. (17)

ACAT role change: The role of the Aged Care Assessment Teams (ACAT) has been reduced.

“I don’t think ACAT does any real support of people with dementia anymore which I think is a resource we have lost and a skill base we have lost” (28)

As a direct result, DOS finds itself having a greater role in case management, prolonged episodes of care and increased caseloads as it tries to fill the gap left by the changes in ACAT.

Policy initiatives to increase rate of early diagnosis: Policy initiatives to support earlier diagnosis will significantly affect DOS workload, particularly if they are not matched with funding to support those newly diagnosed.

“We somehow have to get to the policy makers to see it’s OK to cast the net wide, but the services that DOS provide, that early diagnosis point, we need more of that. We can’t have one without the other”. (28)

Funding priorities: Who gets the health dollar? Participants recognised that clinical interventions performed by DOS staff often result in keeping people with dementia out of acute care, avoid premature placement in residential aged care and indirectly, reduce the workload of the geriatricians. Given the high cost of acute care, the policy and evidence base of how decisions were made about the allocation of health funding was questioned.

“One of the biggest things facing Health is cost. Cost containment. The thing that costs is acute care and its procedures”. (21)

“If (the researcher’s) model is researched, tried and tested and you can present it as that, perhaps there’s more dollars to be attracted”. (16)

Whilst it was not in the scope of this study to measure the impact of DOS on acute care costs, there was agreement that DOS has a positive impact on reducing health costs which is not recognised; and staff felt undervalued.

FINDING 2: THE PRACTICE MODEL

The practice model developed over the past decade has been strongly influenced by all the above factors. With dementia care being an area of growth, DOS's evolution was likened to a

“rhizome type response . . . DOS (has) uncovered new areas and gone into them so that there's areas of case management, there's areas of support etcetera and they've tended to be built up, till you have what you were referring to a the spak-filler approach” (13)

The analysis of the data allowed the practice model of DOS to be identified. The model identifies the target groups, the theoretical foundations, the practice pillars, the core activities and the enablers of the Service. The model is described below. To contextualise the model the key features of the DOS service are listed in Box 1.

Box 1: Key features of the DOS service

- DOS is funded to provide a service to people with early stage dementia. It is not funded to continue providing service to people as they move into the moderate and severe stages of the disease.
- Services to individuals may include home visits, case management, phone support, assistance with behavioural problems, advocacy, referral and liaison with geriatricians.
- Group services may include the Living with Memory Loss program, education sessions, carer support programs and cafe groups.
- DOS consults with colleagues who have specialist dementia knowledge.
- DOS joins with other not-for-profit community services to provide some of the group programs, which are offered in several towns.
- DOS is based in Ballina. Work is allocated geographically to minimise staff travel time and to enable staff to network within their geographic area.
- At the time of writing DOS provided a face to face service to 280 people diagnosed with dementia plus their carers.

Target groups

DOS has two target groups. The first group comprises people with early stage dementia and their family and carers. The second target group comprises the community partners. Although unexpected, this finding highlighted the pivotal and valued role that DOS plays in supporting the community service sector.

Theoretical base

The two principal theories that inform the Service were identified. The first is a knowledge base about the nature of the illness of dementia.

“There is something specific about the nature of this illness . . . the complexity of presentations, the unpredictability . . . the impact of the illness at every level that makes it different to other medical conditions”. (24)

This knowledge encompasses an understanding of the bio-psycho-social nature of illness and the need for a bio-psycho-social approach to dementia care.

“If you look at dementia only in the biological model, everything will fall to pieces . . . the impacts of it are the bio-psycho-social and if you don't try to deal with it that way, everything will implode and you will create a lot more problems than you'll ever solve . . . because traditional clinical pathways don't work”. (20)

The second theory is person-centred care. To the staff at the Service this meant knowing your clients, being client-directed, staying close to the people you serve, being responsive to their changes and offering a menu of programs.

“What DOS is doing is getting alongside people” (15)

“I see DOS as being a very client centred model . . . that being able to identify what people see as needs and that then those things are addressed. So it can be very specific to that particular client, whether it be the family are needing education or the carer's needing counselling or they're needing linking in with services; and that's identified by the client and the carer. (17)

Practice Pillars

Five practice pillars were identified that give the Service stability and strength and through which the Service stays connected with its theoretical foundations. They are:

1. Early Intervention is the provision of support, information and education as soon as possible following diagnosis to ameliorate greater problems, carer burden and health costs as the disease progresses.

"I think those carers DOS starts working with are quite empowered from an early stage, from that initial visit really . . . and because the DOS workers build that relationship with them and they get to understand their level of understanding, they flow that information on as much as that person can actually take on, depending on their capacity; . . . they don't overwhelm them, so that information's available when they are ready to accept it". (19)

2. Outreach is an essential feature of DOS. Going out to visit people in their own households and communities gives clients better access to the Service and clinicians better insight about the client.

"I get lots of false information in a consultation room because I don't have time and it's an artificial setting; and you know that the (DOS) person is going out there, it's one of the things I love about DOS; they are going out to someone's home and they get the real story". (21)

3. Clinical expertise of DOS staff was valued by participants in all focus groups. Several areas of expertise were identified as essential for DOS staff. Firstly DOS staff needed high level communication and people skills.

"Some of those strategies, for me, are engaging someone. We all do it differently; we all have our, what I call . . . my box of tricks that I use, which to me is a skill or a knowledge that I have gleaned from having worked with carers and with people with dementia over a lot of years . . . I can go in and start this conversation and not have someone engaged and go OK I need to quickly look around this house and see this is important, that's important, the garden's important, or the animals are important, those are skills, that you develop . . . over your working life". (14)

High-level assessment, intervention, management and therapy skills are required. Other expert skills needed for DOS work include group work, community education, community development and reflective practice.

"There's a real skill in knowing what role you need to take on board in that situation, because some people really rely on you for advice, some people are really not interested in hearing what you have to say about the medication, they really just want to have your ear . . . and that can change in a matter of a couple of minutes". (23)

Clinical expertise is accessible to both target groups; to people in their homes via an outreach service; and to the community partners via consultation and mentoring.

"Clinical expertise is key for me, and the accessibility, it's like a bridge of clinical expertise into the community, into the sector". (24)

4. The DOS multidisciplinary team allows a group of experienced clinicians from different disciplines to contribute their skills and knowledge to clinical work, rather than each becoming expert in all areas. It relies on professional respect, trust, knowing the limits of one's expertise and a willingness to learn from each other. It is enhanced by access to multidisciplinary expert colleagues and clinical governance structures. Community partners valued the multidisciplinary team.

"I don't think it's just DOS as individual members, it's the multidisciplinary team . . . it's that reassurance and support that's available when you need that for your clients that you have in common, even clients that you don't have in common". (15)

It was also valued by staff.

“There’s something very reassuring about having a bank of expertise backing you . . . for me, the expertise, the shared passion, shared expertise, is like wind beneath your wings; there isn’t anything you can’t achieve . . . with that behind you. It’s very important to me”. (22)

5. A cohesive sector response: DOS works with the community partners to build a cohesive sector response for people living with dementia. DOS works in several ways to build cohesion. The Dementia Pathways Forum and joint ventures foster collaboration and shared frameworks about dementia care.

“There’s no such thing as an ownership thing; you are looking at it from the client’s needs and who the client is. So that’s something DOS has fostered; and you’d see that this morning . . . at the meeting (Dementia Pathways Forum); no one sits here as coming from “their agency” in an ownership sense; everyone comes here on a shared basis of looking at the goal which is presenting good service to your clients with dementia. And that’s a philosophy, it’s a good philosophy”. (12)

Building cohesion requires DOS to take leadership and be accessible and responsive to the community partners. The Service’s open door philosophy was seen as enabling that sector building.

“If they didn’t have the open door policy, if they weren’t out there in the community and supporting us as they are in every aspect I don’t think we would be as cohesive as a group; we wouldn’t possibly even know each other; so you know it’s really keeping things flowing, keeping the flow of services for people”. (12)

It also requires DOS staff to work to know and be known in their local communities.

“A big thing with DOS is that partnership with community services, with communities at large, being out there having good partnerships is so important for that family, for the people with dementia, for the whole lot, you need to involve the whole community . . . recently I’ve done lots of work at [town] . . . and you can see in a small community just those changes, where you get to talk to people in the community and they get it! And that’s a beginning!” (14)

Core Activities

Seven core activities of DOS emerged from analysis of the data. These activities support people living with dementia and the community partners.

Lead: the role of lead agency in the dementia network was a founding requirement of the funding body. Being the only service with a sole focus on dementia and covering the entire far north coast, DOS was in a natural position to take that leadership role. Chairing the Dementia Pathways Forum for eleven years has not only cemented that lead role but also allowed DOS to engage in leadership activities.

“That planning is particularly valuable because it gives us all the opportunity to have input . . . and that’s extremely important; that over-arching planning; (that) strategic plan that they are putting into place”. (15)

“(I) touch base with a lot of different other service providers and (with other services) there doesn’t seem to be that standard that’s filtered down from the top, that just makes everything flow”. (11)

Respond: “Flexibility” was one of the most used words in all focus groups. In summary, DOS has a flexible approach with clients and a flexibility of response with community partners.

“I think that’s what’s essentially DOS: you’ve had a mindset that one size doesn’t fit all; you’ve had that flexibility and you have created other ways of delivering your service that might meet certain needs”. (28)

Link: DOS links people living with dementia with each other to break down isolation by creating a community of people living with dementia.

"I see it as linking with other people and support . . . because people (are) being brought together to share that common experience and support each other because you can't support them forever but they can help to support each other". (17)

DOS links community partners with each other.

"Because you have DOS across the three valleys they're got the links with every single service provider and they know what we all do and they know how we can work, not only with them, but with each other as well".(19)

DOS links clients with specialist services.

"Sometimes people have had reactions and just stopped the medications and they don't let me know; and that's one of the other major advantages of that follow through that at least we've got someone who knows what they should be on, has some knowledge base about medication . . . that feedback I find very helpful". (21)

Innovate: DOS has initiated client programs; for example, carer support programs, social programs and information sessions for people newly diagnosed.

"The thing with DOS is they're prepared to develop and to put forward projects and do things themselves in the community . . . they are getting in there and trialling things". (12)

DOS has also developed training programs for the community sector, including a Certificate IV course in Community Work and the community care module of the e-learning program, "A Positive Approach to the Care of the Older Person".

"What's built is that strength over the years; DOS have introduced innovative programs and . . . we all did the Cert IV, A Positive Approach". (15)

Build: When links are created and programs initiated, the Service has used co-facilitation and collaboration with community partners to build a cohesive sector response.

"They can talk to us about (programs) in meetings, and sometimes hand over to organisations to support that particular group once they have stepped out of it. . . talking to us about it, (and) also being able to mentor us in the community as well". (12)

Consult: With good access to the expert health colleagues, plus expertise within the team, the community partners appreciated the staff's accessibility for consultation. They agreed that, when needing support regarding a client, they would ring DOS rather than the 24-hour hotlines because DOS always got back to them and in most cases knew their clients. Professional support for new workers was also identified.

"When I first started in my role. . . I think that the support that I got from DOS and the Dementia Pathways Forum was what's helped me develop to how I am now . . . all I had to do was pick up the phone and ring DOS". (10)

Manage: DOS is currently working with 280 people with a diagnosis of dementia, plus their carers.

"the model reflects support for the carer; support for the care recipient, support for us . . . you're doing the education, you're doing the clinical, you're doing the carer support, you're doing referral, you're doing all of those different elements; if one was missing, it wouldn't be balanced". (12)

There was much discussion and some disagreement about whether DOS does engage in case management, and whether it should; and whether DOS staff fit the role of key worker. Whilst these issues were not resolved, the discussion highlighted the complexity and demands of the DOS role.

“DOS have a lot of clients on their case load at the moment without case managing. Once they did case manage, you know their load would be choooomp, like they’d be stuck with these clients for a long time and have no capacity to float them through . . . and that’s why I’m not agreeing with that case management side of things, because DOS has a focus on education, carer support, getting that information out there, let alone being bogged down with the case management”.
(25)

“Maybe it’s not a clear cut thing. Maybe it’s hard to separate case management from all the other things you are involved in. Maybe it’s not an easy distinction to make while you are doing it”. (17)

Enablers

The research process clarified a number of process and people factors that enable the Service to work.

Process Enablers:

- Appropriate mix of multidisciplinary knowledge and skills
- Ongoing professional development
- Regular service planning by whole team
- Access to and good relationships with expert colleagues

People Enablers:

- Shared philosophy, shared values, shared commitment
- Leadership: flexible, consultative and collaborative
- Strong work ethic
- Balanced mix of personalities

FINDING 3: EXPERTISE

It was identified that a rural outreach service requires mature, experienced staff with a range of expertise, as they are on the road alone, often not returning to base for several days, and dealing with complex presentations. Their expertise needs to be up to date to stay ahead of the changing client demographic. The range of clinical skills required for the client target group, and the community development skills required to engage with community partners are not necessarily taught in all nursing and allied health disciplines; and few of those skills are shared across disciplines.

A discussion about what theory, knowledge and skills are required to do the work and what qualifications and disciplines can be expected to possess them began in the first focus group and was expanded on in subsequent groups. It included discussion about the usefulness of a competency framework to inform staff selection and training⁽⁹⁾. From the analysis of those discussions, the following key points emerged.

Knowledge: assumed

Certain knowledge is assumed or taken for granted. This was particularly true for communication and people skills; for example, putting people at ease, safety in home visiting, and setting professional boundaries. It was explained that such knowledge was assumed because of the high level of experience of the staff. Staff commented during the research that they had not recognised how much knowledge and skill they had accumulated and that was held by team members.

Knowledge: source

Identified sources of learning were (a) undergraduate, discipline-specific study; (b) experience developed over one's working life; (c) training specifically undertaken for the DOS role (for example, group facilitation); and (d) on the job learning, from experts and from carers of people with dementia (for example, about medication, and strategies for managing behaviours).

"Having travelled the journey with the carers and with someone with dementia you know the learning, it's not an academic thing, it's an actual experienced thing, that you take in because of your involvement and empathy". (29)

Knowledge: gaps

Staff identified some knowledge gaps which were mostly related to discipline based training. For example, community development is not part of the curriculum for nursing and speech pathology, and brain anatomy and medication are not part of social work education. The differing orientation of the disciplines was noted. For example, nursing was described as being oriented to the superficial, physical aspects of care whereas social work was oriented to the deeper layers of caring for a person.

DOS role is not discipline specific

Staff selection for DOS has not been dictated by discipline, and over the years staff have been recruited from three allied health disciplines plus nursing. To manage the large rural area that DOS services, work is allocated geographically. Hence all staff perform much the same role, irrespective of discipline. Whether DOS should continue this practice was discussed but not resolved. Whilst the current practice places a load on staff, having expertise located with each and all staff gives the Service credibility within the sector. This is considered to be particularly important in the rural setting. Furthermore, having a range of disciplines has contributed to DOS developing a model that recognises the dual importance of building a cohesive sector and providing a direct clinical service. Three strategies used to manage the differing discipline base were identified. These are:

- Staff focus on aspects of the role that match their knowledge and skills, and hence may perform the role differently from each other;
- Staff seek training, both formal and informal, to gain knowledge and skills they lack;
- Staff consult with and learn from team colleagues, for example, through the co-facilitation of groups and clinical supervision.

Despite differences, it was recognised that all the team operated using a cycle of care which is common to health professionals, although the disciplines use different jargon.

"The basic nursing process is something that is in my head all the time. It's assess, plan, implement, re-assess". (29)

Level of Qualification and service model

The link between level of qualification and service model was made. Working with dementia is complex and requires the practices of person-centred care. DOS expect staff to be self-directed and self-motivated, to work in outreach roles unsupervised, and to provide clinical interventions. Hence the DOS role requires relevant tertiary qualifications plus sufficient experience to be able to translate theory into practice. Self-reflective practice, knowing the limits of one's expertise, and a willingness to consult were considered essential attributes.

Personal Qualities

In addition to qualifications and experience, some personal qualities were considered necessary to perform the role; these included compassion, sensitivity, openness, empathy, flexibility and humour.

Multidisciplinary team

“There is a lot of evidence right across the world that says that multidisciplinary teams are the most effective way of managing ageing population . . . because of the multi-factorial nature of the population you are dealing with”. (20)

The multidisciplinary team was highlighted as a strength of the Service; and the strengths of this particular team were described as, a willingness to embrace new skills and a confidence to draw on the bank of expertise within the team. There was an appreciation that individual staff did not require a knowledge base as broad as that of the combined team yet could remain confident in their own discipline knowledge and skills and contribute these to the team.

FINDING 4: SHORTFALLS

Whilst the data contained a lot of positives about DOS, the shortfalls in the Service were also discussed. Participants identified the source of most shortfalls as resource constraints, distance, funding anomalies and limitations of the model in servicing some groups. The shortfalls are listed below.

Lack of service and model for Aboriginal population

“It hasn’t been tackled in a systematic way but we need a DOS for Aboriginal people on the far north coast; and that’s something that has never been adequately addressed”. (18)

DOS service not available for people with moderate to severe dementia

The dementia journey from diagnosis to death spans many years. Yet as it is funded for early stage dementia only, DOS withdraws as people move along the pathway into moderate and advanced stages of dementia; other services that provide direct, hands-on care take over.

“I think that it would be great to have the funding so that you could go further along the pathway; you are the experts, that’s what you do, you have been here for this journey, wouldn’t it be wonderful to be able to continue that journey”. (12)

The DOS model was seen as an appropriate model for people as they continue to deteriorate; however the current funding does not allow for this.

Inequitable access

DOS is inaccessible for many people as they cannot obtain a diagnosis of dementia. For others, the lack of a funded care pathway for people with dementia in the health and community sectors has meant that a referral to DOS is not necessarily a part of care planning.

Community awareness raising

Raising community awareness of dementia has not been core business for DOS.

“I think where the model has fallen down . . . is the community development aspect . . . creating dementia-friendly communities is a role . . . and DOS was uniquely placed to do . . . but were never funded to do it”. (18)

Community partners: overlaps and gaps

There are some areas in which DOS and community partners are providing overlapping services; for example funding overlaps have led to two services conducting carer education in one area. In other areas, community partners would appreciate a greater presence from DOS; for example, the distance from the Ballina base of one regional town limits the DOS worker’s availability to do some joint work.

DISCUSSION

Four themes were identified in the literature review: person-centred care, carers, models of community care, and integrated and innovative care. Person-centred care emerged as a foundation theory which informs the DOS practice model. DOS staff were perceived to have a person-centred philosophy and practice.⁽¹⁵⁾ DOS's inclusion of the carer in both home visiting and group work fits with the notion of welcoming family.⁽¹⁴⁾ Proactive models of health service delivery were seen as desirable for managing the growing number of people with dementia, yet participants found it difficult to see how person-centred care could continue to be practiced in a health service that is moving to reactive models of health service delivery.⁽¹⁵⁾ Increasing caseloads have been shown to shift practice from proactive to reactive⁽²⁰⁾ so whilst DOS staff may have a philosophy of person-centred care, the current caseload of 280 people, serviced by 3.6 (current) staff was seen to threaten the practice of person-centred care.

At a sector level, DOS has been instrumental in identifying areas of local need so that growth funds could be targeted to those areas. With the shift to Commonwealth funding, DOS's voice in getting services delivered to emerging areas of need has been lost; and with it, the opportunity to advocate for the provision of person-centred services to people in those areas.

Supporting carers has been integral to DOS practice. Since receiving specific funding to target carers, DOS has implemented educational, psycho-educational and social programs to support and educate carers. The study found that some community partners have come to rely on DOS to perform this role, and hence not built the capacity in their own services, even when funded to do so. Hence there is systemic challenge to provide funding for carers that is separate to the funding for the person with dementia, and to build capacity in the community sector to meet the needs of carers.

The DOS role in case management is an unresolved issue. Case management suits people living with dementia⁽²⁰⁾ as it is a collaborative process of integrating and coordinating care through the health and community service system^(20, 27). Three success factors for case management are, the central position of the case manager in the dementia sector; the embedding in a multidisciplinary team; and the linking of case management to medical decision making⁽²⁰⁾. Hence DOS staff are well placed to provide case management, and to some extent they do. Yet case management is only one of the seven core activities of the Service. The intense clinical involvement it requires can use up all of the Service's capacity, leaving it with little capacity to do the six other valued activities.

Memory clinics assist doctors make a diagnosis by providing a bio-psycho-social assessment of people with memory concerns. Memory clinics were part of the DOS model until recently when the Service made the difficult decision to cease them due to resource constraints and increasing referrals of people with a diagnosis. Whilst policy^(2, 10) supports early diagnosis, and studies support case management from pre-diagnosis⁽²⁰⁾, adequate resourcing for early diagnosis and support requires a system-level response. They cannot be maintained locally without adequate resourcing.

The environment in which DOS operates presents challenges and opportunities. DOS has played a pivotal role in integrating care on the far north coast by building a cohesive community service sector. The Service has also been innovative in introducing programs for people living with dementia and education opportunities for community partners. However there are limits in what DOS can achieve. The assertion that such limitations require system level changes that are often beyond the reach of the typical small primary care practice⁽²⁹⁾ seems applicable to this small rural outreach service. Callahan et al 2009 argue for a more integrated approach with coordination across all providers including community care.⁽²⁹⁾ Whilst DOS and the Dementia Pathways Forum have had considerable success in

creating a cohesive sector response locally, this is not matched at the State level as implementation of the NSW Dementia Services Framework⁽¹⁰⁾ has not been finalised at a policy level; nor at the local health service level which does not have a community care model nor a single management structure for aged services.

A finding from the study was that clinical expertise and the multidisciplinary team were important and valued parts of the DOS practice model. The need for clinical expertise to manage the increasing number and complexity of people with dementia was cited in the literature^{(20) (29)}. DOS has a particular role in providing clinical expertise to people living in the community and the community partners. Whether the importance of clinical expertise will be recognised in the practice models funded through the aged care reforms is unknown; the possibility that such expertise will not be included was of concern to all participants in the study. If clinical expertise is to be maintained, then DOS will need to continue its practice of selecting well qualified and experienced staff⁽²⁰⁾ from a range of disciplines. Maintaining representation from a broad and relevant discipline base may be difficult due to workforce shortages in all clinical groups⁽⁵⁾. It is hoped that a dementia care competency framework will aid in the selection of staff and assessment of training needs⁽⁹⁾.

The practice model described in this study contributes something new to an area of practice that lacks literature about models of community outreach for people living with dementia. The theoretical foundations, practice pillars and core activities described are applicable to both rural and metropolitan settings. The model provides a useful template for community outreach models for all stages of dementia care.

The light that this study shines on the influence of external determinants on the service delivery model is timely in the current Australian context of infrastructure reforms; this understanding can inform aspects of aged care and workforce policy.

DOS will need to continually reassess what is within and what is outside its control and make decisions, based on the practice model, about how to move forward in these challenging times

CONCLUSION

This study has described a practice model for a rural dementia outreach service. The model identifies two target groups: people living with dementia and the community partners with whom the Service collaborates. An understanding of the nature of the illness of dementia, and person-centred care, form the theoretical foundations of the Service. The five practice pillars of the model are early intervention, outreach, clinical expertise, a multidisciplinary team, and a cohesive sector response to people living with dementia. The model articulates the seven core activities of a dementia outreach service; these are leading, responding, linking, innovating, building, consulting and managing. Process enablers and people enablers were clarified. This practice model has led to the Service's pivotal role in *"keeping things flowing"* for people living with dementia.

The study explored the theory, knowledge and skills required for the Service. This exploration highlighted the value of clinical expertise and the multidisciplinary team to both the staff of the Service and the community partners.

Multiple external determinants have shaped the development of the model. The determinants include demographic changes, policy reforms and challenges in the health and community sectors. Flexibility and responsiveness were identified as key to maintaining person-centred care at the forefront of DOS.

RECOMMENDATIONS

This study provides recommendations at several levels that relate to integrating and managing a response to the growing number of people living in the community with dementia.

Commonwealth and State governments

Infrastructure reforms are required at state and national level to respond to the challenge of dementia.

1. Providers of dementia services should adopt a bio-psycho-social approach which includes access to medical, psychological and social expertise as a support to staff and clients.
2. Clinical expertise should be inherent in national policy and funding for dementia care.
3. The multidisciplinary team should be inherent in service delivery models for community dementia care.
4. Service delivery models should be evaluated to ensure that clinical expertise is reaching those who need it.
5. Building a cohesive sector response should be recognised as an expert skill, and adopted as a practice for integrating community care.
6. The carer of the person with dementia should be recognised separately in funding models.
7. Culturally appropriate models of dementia care for Aboriginal communities should be developed and funded.
8. Initiatives to promote early diagnosis of dementia should be matched with services to support those who are diagnosed.
9. The practice model described in this study should be considered as a template for developing new, and re-designing old, community dementia services under the aged care reforms.
10. Research should be undertaken into the cost and the benefit of clinically-based community outreach models of dementia care to the health and aged care system.

Far North Coast Dementia Pathways Forum

It is at the local level that services are delivered to people living with dementia; the following recommendations are to improve the local service response on the far north coast.

11. The Dementia Pathways Forum should to continue its work in building a cohesive sector response for people living with dementia by:
 - a. Updating the Terms of Reference to include the concept of a cohesive sector response;
 - b. Developing strategies to continue to build cohesion; and
 - c. Including those strategies in future action plans.
12. The Dementia Pathways Forum should develop strategies that build capacity in community partners to meet the needs of carers, and include the strategies in future action plans.
13. The Dementia Pathways Forum should identify strategies for building capacity to stay ahead of changing demographics, and include the strategies in future action plans.

The Dementia Outreach Service

DOS is well placed to be a study site for further research, in particular research about:

- a. The cost and benefit of community outreach models to the health and aged care systems;
 - b. The inter-disciplinary competency framework;
 - c. Evaluating the effectiveness of this model on client outcomes.
14. DOS should take action to make the Service available to other researchers as a study site.
 15. DOS should use a competency framework to benchmark staff competencies.

REFERENCES

1. Australian Health Minister's Conference. National Framework for Action on Dementia 2006-2010: NSW Department of Health; 2006 [11/06/13]. Available from: [http://www.health.gov.au/internet/main/publishing.nsf/Content/B9616604C02332D5CA25701B0075A997/\\$File/NFAD%20low%20res%20Web%20Version%20Oct%2006.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/B9616604C02332D5CA25701B0075A997/$File/NFAD%20low%20res%20Web%20Version%20Oct%2006.pdf).
2. Commonwealth of Australia. Living Longer, Living Better 2012 [11/06/13]. Available from: [http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/\\$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf).
3. Australian Institute of Health and Welfare. Dementia in Australia. Cat. no. AGE 70 Canberra: AIHW; 2012 [11/06/13]. Available from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422943>.
4. Access Economics. Keeping dementia front of mind: incidence and prevalence 2009-2050 Australia 2009 [11/06/13]. Available from: http://www.fightdementia.org.au/common/files/NAT/20090800_Nat_AE_FullKeepDemFrontMind.pdf.
5. National Health Workforce Taskforce. Workforce Innovation and Reform: Caring for Older People Australia 2008 [11/06/13]. Available from: <http://www.ahwo.gov.au/documents/Innovation%20and%20Reform/Caring%20for%20older%20people%20discussion%20paper%2012-2008.pdf>.
6. Keane S, Smith T, Lincoln M, Fisher K. Survey of the rural allied health workforce in New South Wales to inform recruitment and retention. Australian Journal of Rural Health. 2011;19(1):38-44.
7. Health Workforce Australia. Workforce Innovation: Caring for Older People Program Final Report 2012 [11/06/13]. Available from: <https://www.hwa.gov.au/sites/uploads/caring-for-older-people-final-report-201205.pdf>.
8. Dewing J, Traynor V. Admiral nursing competency project: practice development and action research. Journal of Clinical Nursing. 2005;14(6):695-703.
9. Traynor V, Britton N. Dementia Care Competency Framework [documentation not released] [18/06/2013]. Available from: <http://media.uow.edu.au/releases/UOW145890.html>.
10. The NSW Dementia Services Framework 2010-2015. NSW Department of Health 2010 [18/06/13]. Available from: http://www0.health.nsw.gov.au/policies/gl/2011/pdf/GL2011_004.pdf.
11. Department of Health and Ageing. Commonwealth HACC Program Manual 2012 [11/06/13]. Available from: [http://www.health.gov.au/internet/main/publishing.nsf/Content/2F4764279BE70622CA257A2300091BFF/\\$File/HAAC%20Manual_web.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2F4764279BE70622CA257A2300091BFF/$File/HAAC%20Manual_web.pdf).
12. PRP Consulting. Review of Ageing Grants Funded Dementia Advisory Services [unpublished]. 2008.
13. Kitwood T. Dementia Reconsidered. UK: Open University Press; 1997.
14. Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. Journal of Clinical Nursing. 2010;19(17-18):2611-8.
15. Kirkley C, Bamford C, Poole M, Arksey H, Hughes J, Bond J. The impact of organisational culture on the delivery of person-centred care in services providing respite care and short breaks for people with dementia. Health & Social Care in the Community. 2011;19(4):438-48.
16. Gibson G, Timlin A, Curran S, Wattis J. The impact of location on satisfaction with dementia services amongst people with dementia and their informal carers: a comparative evaluation of a community-based and a clinic-based memory service. International Psychogeriatrics. 2006;19(2):267-77.
17. Graessel E, Stemmer R, Eichenseer B, Pickel S, Donath C, Kornhuber J, et al. Non-pharmacological, multicomponent group therapy in patients with degenerative dementia: a 12-month randomized, controlled trial. BMC Medicine. 2011;9(1):129.
18. Downs M, Small N, Froggatt K. Explanatory models of dementia: links to end-of-life care. International Journal of Palliative Nursing. 2006;12(5):209-13.
19. Gaugler JE, Mittelman MS, Hepburn K, Newcomer R. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. BMC medicine. 2010;8(1):85.
20. Minkman MMN, Ligthart SA, Huijsman R. Integrated dementia care in The Netherlands: a multiple case study of case management programmes. Health & Social Care in the Community. 2009;17(5):485-94.

21. Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences*. 2009;64(6):788-98.
22. Haberstroh J, Neumeyer K, Krause K, Franzmann J, Pantel J. TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental Health*. 2011;15(3):405-13.
23. Burgio LD, Collins IB, Schmid B, Wharton T, McCallum D, Decoster J. Translating the REACH caregiver intervention for use by area agency on aging personnel: the REACH OUT program. *The Gerontologist*. 2009;49(1):103-16.
24. Schulz R, Burgio L, Burns R, Eisdorfer C, Gallagher-Thompson D, Gitlin LN, et al. Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions. *The Gerontologist*. 2003;43(4):514-20.
25. Smith SA, Bell PA. Examining the effectiveness of the Savvy Caregiver Program among rural Colorado residents. *Rural & Remote Health*. 2005;5(3):466.
26. Brown J. Quality Support Groups Research Project Phase III North Ryde: Alzheimer's Australia NSW; 2009 [11/06/13]. Available from: <http://www.fightdementia.org.au/common/files/NSW/20110610-NSW-RPT-Executive-Summary-QSGRP-Phase III.pdf>.
27. Sargent P, Pickard S, Sheaff R, Boaden R. Patient and carer perceptions of case management for long-term conditions. *Health & Social Care in the Community*. 15(6):511-9.
28. Borbasi S, Emmanuel E, Farrelly B, Ashcroft J. Report of an evaluation of a nurse-led dementia outreach service for people with the behavioural and psychological symptoms of dementia living in residential aged care facilities. *Perspectives in Public Health*. 2011;131(3):124-30.
29. Callahan CM, Boustani M, Sachs GA, Hendrie HC. Integrating care for older adults with cognitive impairment. *Current Alzheimer Research*. 2009;6(4):368-74.
30. Koshy Elizabeth KV, Waterman Heather. *Action Research in Healthcare*. London: Sage Publications Ltd; 2011.
31. Morton-Cooper A. *Action Research in Health Care*. Oxford: Blackwell Science Ltd.
32. Abbey J, Palk E, Carlson L, Parker C. *Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community*. Brisbane: QUT: 2008.

APPENDIX 1

Questions asked in focus groups

Group 1	Participants: DOS Staff
Q 1a	What are the tasks that you do in your job? (brainstorm)
Q 1b	How would you categorise these tasks under general headings?
Q 2a	We've now identified a wide range of tasks, and categorised some under different headings. And I'm aware that you are a multi-disciplinary team, so you'd have different training experiences and therefore different skills and knowledge. What I'd like to ask now is - what are the skills and knowledge that you rely on to do the various tasks in your job?
Q 2b	Are there other skills or knowledge that would be useful for DOS work, or that you would find valuable to have?
Q 3	I'd like to ask you to think about what would be the knowledge/skills/theories/ways of working that you might take for granted in doing your work. What are your underlying assumptions about how you go about your tasks? For example, when someone is complimented on their work, often the common response is that 'it's just what I do'. Can you describe how you come to know 'what you do'? Finally, what understandings, attitudes, knowledge, skills & theories have you heard about today that you didn't learn about in your discipline/training?
Closing	Wrap up: Final comments
Group 2	Participants: Community Partners
	<i>Brainstorm 1: From your knowledge, expertise and experience, what do people living in the community with dementia and their carers need? (A quick brainstorm to warm up; not a test).</i> <i>Brainstorm 2: Many of you have worked in community dementia care for some time. You are here representing the community sector for dementia care. What do you, your workers and your agency need to support and sustain you in this work?</i>
Q 1	Thinking about all of these needs you have identified for the person with dementia, the carer, the workers in the community sector, what does DOS provide? And how does DOS provide it?

	<p>Prompt Qs:</p> <ul style="list-style-type: none"> - If you think about your clients, when and how would they relate to DOS? - How does DOS impact/influence your clients' lives? In what ways? - What about in terms of community classes, other programs?
Q 2a	Are some of these things that DOS provides things that your service cannot provide?
Q 2b	Are they additional or complementary to what you and your service provide?
Q 3	Are there things that DOS doesn't provide that you think it could, or should?
Q 4	Over the years you have known DOS, have you noticed any changes in the DOS model and if so, what are those changes?
Closing	Wrap up: Finally, can you make any general comments about the DOS model
Group 3	Participants: Dementia and Discipline Experts
Q 1	What is your understanding of the DOS model of service? How would you describe the model?
Q 2	What are the shortfalls in the model that you see/experience in the current DOS model?
Q 3	What improvements can be made to this model to ensure that it is consistent with current theory and evidence-based practice?
Q 4a	What are the clinical skills and knowledge base and theoretical base that is needed for the DOS service.
Q 4b	Ancillary Q: does everyone in DOS need to have all of this knowledge and/or is it sufficient that DOS have access to this knowledge rather than have it all themselves?
Q 5	Of the knowledge/skill base identified, is any of it discipline specific?
	<i>Presentation: Five minute overview of feedback from FG1 and FG2, with summary and two flow charts.</i>
Q 6	Any comments on what you have just heard/read, or any final comments.
Group 4	All Participants
Q 1	In your current role, what are the three things that you think are essential for a successful DOS. Only allowed three points per person. Answers on butcher's paper. (Not for discussion; just for tuning into topic).
	<i>Presentation: Researcher to provide findings for member checking and to elicit new information.</i>
Q 2	<i>Feedback/Questions of researcher re presentation:</i> From what you said in the focus groups, are there things that stand out that are wrong, or out of context or glaring omissions.
Q 3	Keeping in mind what is out of DOS's control and what is in DOS's control: What is essentially DOS? (Sub-areas facilitator can pull out: Multidisciplinary team; target groups; community versus client; carer support: how big a part of our role? Case management versus key worker; If we have to prune it, what stays, what goes?)
Q 4	You want to improve the current model for a rural dementia outreach service. What comes to mind?