

**Consumer Empowerment and Service Delivery
ADI – Delhi Regional Conference**

November 2014

My sincere thanks to the organising committee for inviting me to give a presentation on the theme of consumer empowerment and service delivery.

I feel passionately that without consumer empowerment, choice and flexible services, we will not see the changes in the delivery of support and services to people with dementia and their family carers that are necessary to ensure a better quality of life.

When I stood for election for the Chair of ADI I said that there was a strong consensus that ADI has come a long way in recent years, but an equally strong view that the Board of ADI should take a stronger leadership in key areas.

Among the four areas that I identified for strong leadership was the need for ADI to be a truly international consumer body. I suggested that to do this we needed to do more to empower people with dementia and their family carers if they are to be partners in care, to have choices, and to truly participate in the community.

Talking about choice and empowerment may be a distant dream for the many countries who have a poor or non-existent service infrastructure. But in framing your dreams I hope you can learn from the successes and failures of developed countries. And I think we have failed most in not making consumers partners in care and an excessive focus on residential care.

Thirty years ago when I first became involved in aged care policy and program delivery I think it was true to say – at least in Australia – that we had within

government very little understanding of what was required in terms of dementia care. Countries around the world within the resources available to them have less excuse today for not doing what we know is best practice in dementia care.

We know what to do in terms of the care and support that is needed but to achieve our goals we need to address two key issues in dementia policy, whether we are talking about acute, primary, community or residential care.

Firstly, that dementia is as much a social condition as a medical one and it is the philosophy of care, dignity and respect that we accord to people with dementia that is so critical.

Secondly, that every person with dementia is unique. This is what makes dementia care so difficult. We talk about models of care in my view at our peril as it suggests one size fits all whereas what we need is a diversity of approaches.

In response to those challenging ideas two new and important courses for change are being adopted.

Firstly, there is the concept of dementia-friendly communities and organisations that enable the participation of the person with dementia in every day life and to have the purpose in life we all seek. It is a welcome development that this concept is being embraced by different countries and is a focus for discussion at this conference.

The other exciting development in my view is the notion of empowering people with dementia and their family carers to take decisions in partnership with healthcare professionals in determining the care and treatment that best responds to their needs.

The dynamic of making the world a dementia-friendly place on the one hand and of consumer empowerment on the other are the real forces for change because they have the power to change the negative attitudes and cultures that have been the pervasive context in which dementia has been thought about for centuries.

There are many strategies that have the potential to increase consumer choice, consumer empowerment and quality of dementia care. But the ones I would like to talk about today are:

- Taking the social action necessary to reduce the stigma and social isolation of dementia.
- Combining person centred care and models of consumer directed care.
- Measures to improve the quality of care and make more transparent the care outcomes being achieved.
- Addressing workforce issues.

Reducing Stigma

I suggest that we have much to learn in aged care from the disabilities movement in respect of legal rights and social participation. In Australia it would be true to say that

aged care consumer organisations have been more conservative than their disabilities counterparts in pressing for legal rights and social action.

I am pleased that this is beginning to change and I hope we are about to see a sea change in respect of the dignity and legal rights we accord to people with dementia through new thinking around dementia friendly communities and organisations.

This audience does not need to be persuaded that a diagnosis of dementia brings with it stigma and social isolation across the world but we do need to remind ourselves that one third of countries surveyed by the world health organisation explained that people with dementia were isolated or hidden because of shame. A research study in Australia found that 60% of those surveyed indicated that if they received a diagnosis of dementia they would feel a sense of shame and half would feel humiliated by the diagnosis¹.

Just this year in Australia we surveyed people with dementia to gain insights into their experiences of living with dementia. Again the results showed just how overwhelming the social impact of living with dementia really is. 59% of people with dementia thought people avoided spending time with them because of their diagnosis and more than 40% of participants wished they had had more social contact².

¹ Survey of Australians about dementia, University of Wollongong, Centre for Health Initiatives 2012

² Living with Dementia in the Community-National Survey Findings, Alzheimer's Australia, Sept 2014. https://fightdementia.org.au/sites/default/files/DementiaFriendlySurvey_Final_web.pdf

One respondent said “sometimes my social death makes me more sad than the changes to my brain and the loss of my memory. It makes me so angry. I just want to be counted as a person again”.

In short stigma and social isolation is still having a major impact on the quality of life of people with dementia.

The rights of people with dementia are being violated across the world daily and there is still a lack of legislation to protect their rights. Only 63% of high income countries have legislation or regulatory standards that protect the rights of people against discrimination on the basis of dementia and only 18% of low to middle income countries³.

To change this we need both to engage our societies more broadly with people with dementia and to better protect their legal rights.

The adoption of dementia friendly communities and organisations in the United Kingdom, Belgium, Japan and Australia has great potential in providing people with dementia with access to services that we all have a right to expect including banking, retailing and health care.

At one level the concept is beguilingly simple in training the staff of organisations on how to communicate with people with dementia, volunteer organisations on how to provide assistance for people with dementia to volunteer and in promoting social

³ Dementia, A Public Health Priority, World Health Organisation, 2012.

activities revolving around art galleries, botanic gardens, walking groups, choirs and supporting groups.

My concern is that this important opportunity for social interaction does not become tokenistic and it may become tokenistic unless it is driven and informed by people with dementia themselves through local dementia action groups.

For this reason and others it is important that we also focus at the national level on the legal rights of people with dementia.

Even when legal protections are in place, often health care professionals and consumers may not be aware of these rights. We recently surveyed close to 800 health professionals about their experiences around end of life care and dementia. 29% of health professionals did not think people had the right to refuse food/fluids at the end of life or were unsure. This is despite there being legal protections in place in Australia to allow for refusal of any medical interventions. 11% thought that refusal of antibiotics was not legally allowed⁴.

We need a three pronged approach to tackling issues of legal rights:

1. Ensuring that there are adequate protections in our legislation
2. Raising awareness amongst health professionals and care workers about the legal rights of people with dementia
3. Empowering people with dementia and their carers to know their legal rights and to be aware of what recourse is available if their rights are being violated.

⁴ End of Life Care for People with Dementia – Survey Report, Alzheimer’s Australia, 2014.

Person Centred Care and Consumer Directed Care

The concept of person centred care dates from the early 1960s and the recognition that there was a need to rebalance the health professional/client relationship to privilege the client and acknowledge their capacity for self actualisation. Tom Kitwood adapted these ideas to the dementia care setting and the rhetoric of person centred care has crept into policy documents and the thinking of care professionals. These days, at least in Australia, person-centred care has become the buzz word of the aged care industry but that does not necessarily mean the goal has been realised.

There are many definitions of person centred care which is perhaps part of the problem but central to the thought is the need for recognition of the connection with the person, a focus on the person's strengths and goals, and interdisciplinary approach and recognition of the centrality of relationships⁵.

Evaluative tools have been developed to monitor outcomes achieved with person centred care and there is evidence to show it:

- Improves client and carer satisfaction⁶
- Improves feelings of professional self worth⁶
- Improves pain management and management of behaviours associated with dementia⁷

⁵ Older People – Issues and innovations in care, Rhonda Nay, 2013, pg 138.

⁶ Person-Centred Health Care Website, NARI, 2006,
<http://www.mednwh.unimelb.edu.au/pchc/index.htm>

⁷ Behaviour Management – A good guide to practice, DBMAS and DCRC, 2012.

- Improves adherence to treatments^{6,7}

The adoption of person centred care has been challenging, in part because definitions vary, the lack of staff training and the lack of staff resources.

But I suggest the missing piece of the jigsaw is the failure to empower people with dementia and their family carers to be partners in decision making. It makes little sense to me to pursue person centred care if it is the gift of the service provider rather than the right of the individual.

Consumer directed care recognises that the consumer, to the extent they are capable, should make choices about the types of services they access and the delivery of those services including who will deliver the services and when.

The outcomes consumers wish to achieve through CDC include:

1. A better match between their goals and the care and support provided.
2. Greater flexibility in the services provided.
3. The capacity to access those providers best positioned to provide the services required.
4. Transparency in the funds available to the individual and the amount used for administration.

CDC and person centred care are often used interchangeably.

There is, however, a vast difference between having consumers at the centre of a care plan and having consumers as partners.

The move towards CDC necessitates a significant shift in the culture and attitudes of both service providers and consumers in the aged care sector – a shift towards engaging with consumers and their family members and focusing on outcomes and achieving goals rather than processes.

This means that providers have to focus on what is important to consumers and how consumers can be supported to meet their own goals rather than providing the care we think is best for consumers.

This can be a difficult balance as the service provider has a duty of care and has to manage risk while also recognising that it is a person's right to choose.

There are also difficult issues to navigate around how to identify goals and needs of the client, particularly around sensitive issues that can be stigmatised such as sexuality, mental health and incontinence.

It is the shift in culture that will empower consumers to make choices and be active participants in their care and for family members and carers to feel valued.

It will require all of us to rethink the ways in which we provide care for people living with dementia.

A focus on consumer choice is gaining momentum across the world. Nearly two-thirds of the OECD countries report that their care services support consumers to make decisions on the sort of care they want⁸. Despite the aims of many organisations to provide consumer directed care, research in the UK has found that organisational cultures contain a variety of barriers to providing this type of care for people with dementia⁹. I think many countries still struggle to apply this philosophy to people with dementia.

Consumer directed care is a spectrum of choice ranging from some involvement in decision making, to cashing out of services, putting money directly in the hands of people with dementia and their families is a promising innovation in terms of consumer directed care and improving service integration, flexibility and choice.

Some countries provide direct payments to consumers to obtain services. For example, Canada has self-managed schemes, providing eligible users with cash benefits to manage care delivery, including paying family carers and friends¹⁰. In the UK direct payments are mostly used by people with dementia for personal care in the home, respite services and services not usually included in care packages, such as gardening supports. A UK survey of people with dementia and their carers found that people using direct payments were more satisfied with their care and services¹¹.

⁸ A Good Life in Old Age, OECD, 2013, <http://www.oecd.org/els/health-systems/PolicyBrief-Good-Life-in-Old-Age.pdf>

⁹ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

¹⁰ Providing and paying for long term care, OECD, 2011

¹¹ Providing and paying for long term care, OECD, 2011

For a long time I have been advocating for a pilot in Australia of direct payments to people with dementia and their carers to purchase respite. This would enable more respite options including paid respite that is provided by family and friends. There are many potential benefits with family and friends providing respite as they are known to the person, familiar with the person's needs and a trusting relationship already formed.

This approach is particularly important for respite as respite services are often not resourced to care for people with dementia, particularly if they have behavioural and psychological symptoms of dementia. Respite services are also rarely available where and when they are needed.

Regardless of where countries are on the spectrum of choice (from involvement to cashing out), for consumer directed care to work, people with dementia and their carers need to be empowered through information, support and funding, and eventually a shift in culture so they feel more valued.

They need to have access to information about their rights and care choices to be able to make informed decisions about their care.

Both the UK and the United States provide information about health service providers' performance online to help consumers choose which provider they wish to receive care from. The UK National Health Service website¹² includes information about service options available, performance indicators and past patients' ratings,

¹² <http://www.nhs.uk/Pages/HomePage.aspx>

comments and experiences. Australia is now working on an opt-in program of publically available quality indicators for aged care facilities. It is starting slow but there is hope that this will bring greater transparency and information - a TripAdvisor for aged care.

For people with dementia choice is only often possible with appropriate one on one support throughout the dementia journey. In Australia we have a network of key workers, funded by the government, for people with younger onset dementia. These workers provide ongoing individualised information and support to people with younger onset dementia and their carers. They support people with dementia to make decisions regarding their own life and care through developing individualised plans based on goals and providing information about local care services.

We are working towards expanding the key worker program to all people with dementia as we see this type of approach as being key in supporting consumers to have greater choice regardless of their age.

The issue of choice also goes to larger questions about the splits between community and residential aged care and how funding for services should be allocated. In Australia there is a rationing system where the number of places increase based on the number of people over the age of 70. The split between community care places and residential is based on an arbitrary formula rather than consumer demand. There is a call in Australia to shift to a system that is more responsive to consumer demand which would replace the rigid splits between community and residential care.

There are a range of challenges including issues around capping spending and enabling appropriate planning but it is clear that we are headed in the direction of a more market based system. This change in funding models is important as it will drive quality improvements, create more flexibility and drive innovation.

For example, a more responsive system could include the option of flexible respite in residential care so that consumers have the option of planned respite in regular blocks of several weeks or more in clusters separate from long term care. At the moment it is a dichotomy and there is no opportunity to use residential care services flexibly and occasionally to support ongoing care in the community.

Japan is moving towards an integrated community care system where community support, health care and residential care is combined to enable older people with dementia to continue to live in their community, while having the option to flexibly move in and out of residential aged care¹³. Japan, as well as Sweden, has also introduced small group homes as an intermediate level of care between community and residential care.

Quality

Good dementia care has to have a focus on quality of care. Quality is a broad term that covers a range of issues from ensuring an adequate environment and living spaces to access to appropriate care.

¹³ Dementia Policy in Japan, Katsuni Hara, Health and Welfare Bureau for the Elderly, Ministry of Health , Labour and Welfare

A person's quality of life very much depends on the quality of care they receive. This was demonstrated in studies in the United States and United Kingdom that found that aged care residents' quality of life varies substantially between facilities rather than within facilities. This is a fascinating finding- it means that differences in quality of life are dependent more on the aged care facility that you reside in rather than the specific health conditions or problems that you may have.

In Australia the focus on quality over the last few decades has been on weeding out the bad apples and ensuring compliance with a basic set of standards.

More than two-thirds of OECD and European countries have compulsory long term care accreditation or accreditation as a requirement for reimbursement or contracting. Accreditation is important as it ensures service providers meet certain criteria and standards to provide care¹⁴.

More and more countries are using consumer involvement in the evaluation and accreditation of health and aged care services to both inform the process and improve consumer engagement.

For example in England consumers work with the Care Quality Commission and are involved in accompanying inspectors on visits to services and participating in the auditing process. Due to their first-hand experience with services, consumers are

¹⁴ Providing and paying for long term care, OECD, 2011

better placed to identify what the key issues are and capture invaluable information that may otherwise go undetected during standard auditing processes¹⁵.

Similarly, the United States have developed a long-term care ombudsman program, where advocates for residents in nursing homes visit facilities and monitor conditions. There are over 12,000 ombudsmen volunteers of which over 9,000 are certified to investigate complaints¹⁵.

Some countries, including England and the Netherlands assess user experience through surveys. Consumers are surveyed about consumer choice, autonomy, dignity, comfort, security, relationships and social activity¹⁵.

In Australia we are taking small steps towards greater consumer involvement with a pilot of consumer “experts” being part of the accreditation team and ongoing surveys of consumers as part of the accreditation process.

But consumer involvement in the accreditation process is not enough.

The time has come for a fundamental shift from compliance, minimum standards approach to one which focuses on improving quality and providing information to consumers about quality of care.

¹⁵ Referenced in: Quality of Residential Aged Care: The Consumer Perspective, Alzheimer’s Australia, 2013.

Less than a third of OECD countries collect quality care indicators systematically and even fewer countries make this information available or grade the performance of service providers based on weighted quality indicators¹⁶.

In the United States nine quality measures are collected by nursing homes which look at all resident's clinical and physical needs and includes measures such as pressure sores, falls, urinary tract infections and restraint use. The quality measures recorded in the United States enable comparisons between nursing homes using a web based tool called *nursing home compare*. This has led to more informed decision making about care options for consumers¹⁷.

Quality indicators will be introduced to Australian residential care facilities as of July 2015. Initially there will be three indicators including:

- prevalence of pressure injuries
- incidence of use of physical restraint
- prevalence of unplanned weight loss

These reforms are likely to evolve slowly. There are complex issues to consider including avoiding creating perverse incentives (for example reducing falls through keeping people in bed).

¹⁶ Providing and paying for long term care, OECD, 2011

¹⁷ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

Regardless of the challenges I am pleased that worldwide we are slowly moving to a world where consumers will have more information to make good choices about care and services.

Workforce Issues

It is evident that the cultural changes required in the way that dementia care is delivered in the context of person centred care and consumer directed care will only be realised if organisations demonstrate the leadership necessary in adopting appropriate care philosophies and in training a skilled workforce.

In Australia there is a frequent recognition that workforce issues are a priority but few, if any, solutions are put on the table. In practice workforce in Australia tends to be governed by regulation and territorial fights between professional and union organisations. It would be a refreshing change in the context of workforce issues to start with the older person and ask what skills and knowledge are required in order to meet the needs and choices of the mix of people in aged care.

In Australia the dimensions of the issue are overwhelming. In a report prepared for Alzheimer's Australia in 2009, Access Economics indicated that by 2029 there would be a shortage of nearly 60,000 paid dementia care staff (representing about 70% of the current workforce) and that there would be a shortage of nearly 95,000 family carers (80% of the current unpaid dementia workforce). These magnitudes are stunning and there are no clearly articulated strategies in place to either address the numbers of workers required or the mix of skills required.

Care workforce issues are prevalent all over the world. There is a 3% vacancy rate in the long term care workforce in England, which is higher than any other employment field, and staff turnover is common. This phenomenon also occurs in America where most states report serious shortages of direct care workers and annual turnover rates ranging from 25% to 100%¹⁸.

Small workforce and low retention is in part due to the low wages provided to care workers. In almost half of OECD countries, wages for care workers were paid two-thirds or less than the average wage. Only in Denmark and Iceland did care workers receive an equivalent average wage¹⁹.

Countries have adopted various strategies to improve these workforce issues including improving work conditions, providing economic incentives, re-training, increasing job responsibilities and encouraging younger people to receive care training and pursue a career in the sector²⁰. It is currently unclear which public policies are likely to be most effective in promoting retention and career development in the direct-care workforce²¹.

There is evidence that upgrading the care profession to a recognised and valued profession can improve worker satisfaction and therefore retention rates. German,

¹⁸ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

¹⁹ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

²⁰ Providing and paying for long term care, OECD, 2011

²¹ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

Dutch and Swedish long term care workers are more satisfied with their working conditions and responsibilities than USA and UK care workers, which has resulted in better retention rates and a larger workforce²². Japan has also worked towards creating the view that long term care is a profession, which has successfully improved their workforce. Public awareness to raise perceptions of care workers can also contribute to improving recognition and value of care workers resulting in better retention and a stronger workforce.

Professionalisation of care workers will come about, in part when training and acquisition of skills is seen as a continuing process of career development, and a striving for excellence rather than merely a question of meeting minimum regulatory standards²³.

Conventional wisdom and the evidence base suggests the keys to good quality care and a satisfied workforce are achieved through organisational leadership, commitment to philosophies and care consistent with person centred care and the Eden alternative, the adoption of consumer directed care, access to training and education for all staff and use of multidisciplinary approaches. Some organisations work to do this and achieve better quality care outcomes.

There are some hopeful initiatives in Australia to help train and support staff to provide better quality dementia care. For example, the Dementia Training Study Centres aim to improve the quality of dementia care by providing development

²² Providing and paying for long term care, OECD, 2011

²³ Journey of Caring – An analysis of long-term care for dementia, World Alzheimer Report, Alzheimer's Disease International, 2013.

opportunities to health professionals. One of their national priority areas is person centred care and they play a fundamental role in facilitating the transfer of evidence-based knowledge, such as consumer directed care, into practice

The Dementia Behaviour Management Advisory Services (DBMAS) also aim to improve the quality of life for people with dementia by up-skilling and supporting service providers and by ensuring care services are responsive to individual and diverse needs. DBMAS staff will look for the underlying cause of a behavioural symptom expressed by a person with dementia and recommend strategies to address this underlying need, such as pain management for undiagnosed pain or some other form of comfort.

A quite touching case study involved an elderly lady with dementia who was distressed and anxious and frequently called out at night. DBMAS discovered that the reason why this lady was distressed was because she believed she was in her 30s and had left her baby at home. Subsequently the lady was given a baby doll which immediately comforted her and reduced her anxious behaviours. I think this example clearly illustrates the benefit person centred care approaches can have not only on the person receiving care but also on care staff.

Other quality dementia care training opportunities that encourage consumer directed care are delivered and provided by Alzheimer's Australia.

But in Australia there is little determination to tackle systemic issues in terms of low pay, low training, poor English language skills and high rates of staff turnover.

Combine this with an ageing workforce and the future is far from promising.

Governments across the world seem to be looking to as part of increased user charges which will force change in management and workforce practices. May be the chill winds of competition and market based approaches will bring some greater hope.

Conclusion

The empowerment of consumers through person centred care and consumer directed models seems to me to hold out hope for the future in achieving better care outcomes. If accompanied by new and more radical approaches to monitoring the quality of care and more transparency to assist consumer decision making it may be that services will increase their flexibility and respond better to individual needs.

Economic forces will necessitate change as governments retreat with constrained budgets and user charges become an increasing feature of the aged care landscape. Consumers are starting perhaps to adopt the language of economists in seeking informed decision making, access to flexible services and a more competitive market place that achieves greater efficiencies and effective service delivery.

My thought is that consumer empowerment is a priority for ADI and an important means of getting real improvement in aged care and dementia services.

Thank you