

# **ALZHEIMER'S UNIVERSITY –MILWAUKEE USA**

**12-14 JULY 2007**

**Seminar conducted by Glenn Rees, National Executive Director  
Alzheimer's Australia**

## **CONSUMER EMPOWERMENT AND ADVOCACY**

I understand this may be the first session of this kind conducted within the Alzheimer's University. I hope it will be the first of many and that we will all come to develop a significant and very practical consumer focus within the work of our organisations.

While the thoughts I offer are my own I received a lot of helpful thoughts from our National consumer Committee and staff on what I might say.

The issue of consumer empowerment and advocacy goes to the heart of what organisations we aspire to be and are perceived to be. Helping people with dementia

With your agreement I would like to conduct the session in two parts.

First, to reach some common understanding with you all about what we mean by consumer empowerment and advocacy.

Second, to identify the elements of a consumer empowerment and advocacy strategy that will have the end result of empowering people with dementia and family carers to speak for themselves.

### **Consumer empowerment and advocacy - What does it mean?**

We all start from different points. Let's start with three questions.

- **What do you think is meant by consumer empowerment?** Points to look for in discussion
  - To enable the voice of a disadvantaged group to heard
  - To enable a disadvantaged group to advocate for their rights
  - To enable consumers to contribute to policy positions
  - To enable consumers shaping service development and delivery
  - Helping people to tell their stories, influence outcomes and, in the process, change our organisations for the better
  
- **Why do you think advocacy is important?** Advocacy can take many forms. An advocate is basically some one – an individual or an organisation who advocates an issue for another. Of most interest to

us perhaps in terms of consumer empowerment is self advocacy – the person speaking for themselves. Points to look for in discussion

- Advocacy can change community attitudes and misconceptions;
  - Advocacy can assist people to gain access to resources, funding and information;
  - Advocacy can help to make service providers and organisations accountable ensuring there is transparency in their actions and decisions;
  - Advocacy can help the individual to have some control over their situation;
  - Advocacy ensures that an individual has a voice and helps it to be heard;
  - Advocacy helps to increase recognition of the rights of people with dementia.
  - Advocacy can also promote positive change to the structure and policy of our organisations, which will be of benefit to people with dementia.
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- **What do you want the political, corporate and community perception to be of your organisation?** Points to look for in discussion
    - dementia experts
    - representing people with dementia
    - representing families and carers
    - advocates who know what they are talking about as the messages are based on real needs and experiences
    - all of the above?.

Two points might be drawn from this discussion.

Firstly, consumer empowerment and advocacy are about helping the consumer to have their voice heard and assisting in protecting their rights.

Secondly, that empowering consumers empowers Alzheimer's organisations because it makes our organisations more credible and our messages more powerful. Our organisations are worth listening to, not just because we are dementia experts, or have doctors on our boards, but because we hear and represent the issues as they are understood by people with dementia and their families and carers. As workers within organisations, it is important that we understand that self advocacy increases the credibility and power of our organisational advocacy.

In summary, empowering consumers strengthens the capacity of individuals to have their voice heard as well as strengthening our Alzheimer's organisations.

## **The Strategies**

The cultures of ADI members may be very different in terms of the openness with which dementia can be discussed. As a consequence there may be some constraints on whether a particular person with dementia or family carer will feel able to speak out.

So let me suggest some strategies based on Australian experience that you might think about using:

### **1. Developing a consumer focus**

In Australia, it is only recently, since 2000, that people with dementia have been fully included in our advocacy. Before that for twenty years or so, the consumer advocacy was largely left to families and carers. So we initiated a debate in 2001 inside our organisation about what being an inclusive organisation means in terms of being of people with dementia and their families and carers. This project was called Consumer Focus Project and it-

- Identified the ways in which people with dementia and carers were involved in Associations.
- Distilled the views of many stakeholders about how the consumer focus of Alzheimer's Australia might be strengthened.
- Pulled together information to guide future legal, governance and insurance decisions.
- Provided a basis for further work necessary to support people with dementia in becoming full partners with carers in the work of Alzheimer's Australia.

The report was perhaps less important than the process in raising the profile of consumers – and in particular, people with dementia - within the organisation. A national consumer involvement policy statement resulted, but more importantly, staff approaches and the involvement of consumers within Alzheimer's Australia were permanently changed for the better. Regular reports are made to Board and consumer focus is now one of our 4 key result areas in our strategic planning.

Have you developed consumer focus? How? What outcomes?

### **2. Promoting advocacy by the person with dementia or their family carer**

This can take many forms and each of us will do it differently. Often the essence is the power of a personal story. The opportunities for advocacy are:

- In the governance of our Alzheimer's organisations
- In the policy making processes within our organisations eg advisory committees, commenting on draft documents
- Contributing to external discussions with Ministers, Departments, wider communities, media.
- Presentations at the openings of conferences/seminars
- Helping to protect the rights of consumers – e.g. consumers who have successfully protected their rights supporting others to protect their interests – insurance issues

- Dementia Manifesto— advocating in elections - establishing priorities for action that would do most to improve the quality of life of people with dementia and their carers.

In Australia the main weight of the effort is in policy making within the organisation and in public presentation (particularly at conferences, media).

What has worked best for you?

### **3. Structures That Promote Involvement in Advocacy**

In Australia we have tried to develop a structure that is inclusive

Firstly, we have a National Consumer Committee that contributes to policy positions of the organisation. It is linked to consumer advisory groups at the local level. There are difficult issues around resourcing both in terms of staff support and in terms of travel dollars. A key question is whether to have separate groups for family carers and for people with dementia.

Secondly, a National Cross Cultural Dementia Network for people from Culturally and Linguistically Distinct backgrounds.

Lastly, a National Indigenous Dementia Advisory Group.

An unresolved issue is how to reach out effectively to lower socio economic groups.

What structures do you have? What do you think would work for you?

### **4. Consumer Events to Get Political and Media Attention.**

In Australia we held a National Summit at the National Parliament building at which were fifty people with dementia and family carers from all parts of Australia. The event itself - and the resulting Communiqué expressing the views of the participants about what they wanted - had a significant impact at the political level and within Alzheimer's Australia in setting policy directions. Subsequently, a National Consumer Committee was formed. That group has developed our Manifesto for our next Federal election and has formed working groups on priority policy areas.

What major consumer event have you organised to empower consumers/promote self advocacy?

### **5. Selecting and Training for Consumer Advocates**

This could be the subject of seminar in itself. We are learning all the time and practice varies widely.

- **How to select consumer advocates?** There are people who are naturally more likely to be advocates but it is a matter of identifying

these people and facilitating/encouraging their more active involvement. We have difficulty finding people because most people approach the organisation in the early stages of dementia and many are still coming to terms with the diagnosis. Carers are so busy providing care that they often don't have the time or energy to be involved.

Staff awareness of the importance of advocacy, particularly in service delivery, is important as these people are in a prime position to facilitate people who are naturally more attuned to advocacy. The importance of having people from different cultural backgrounds

- **What training should be provided?** Generally media training is not available but people are advised prior to an interview e.g. about to what to expect, to not have too high an expectation and for the interview to be a positive experience:
  - TV -to not be surprised if they have a lengthy interview and only get a minute on TV or their story may get bumped off due to other big news stories.
  - Print journalists can sometimes come across as under prepared & disorganised – that is the nature of their work with deadlines and usually the story turns out pretty well.

Most media requests, although on different topics related to dementia, are about the personal experience of dementia – how it affects the family and quality of life – the human interest angle. The advocacy angle is usually covered by a professional in the same story. Occasionally there will be an angle to comment on such as what do you think about government funding of research? We encourage people to talk about their experience and to not impose the stress of having to take a particular line too much. Keep it simple is best.

- **What support should be provided?** Ensure all contact with the media is conducted through the relevant officer
  - Do not provide any names or contact information to journalists until the “consumer” has agreed to do the interview. This is especially important in rural areas where the journalist is likely to know the person or a family member.
  - Wherever possible the policy & advocacy officer or communications officer attend face to face interviews as an observer
  - Ask the consumers' preference for interview location – at home or in a park etc.
  - Ask feed back about their experience with the interview or any concerns they may have
  - Ensure the consumer gets a copy of the interview (print)
  - Send a follow up thankyou to the consumer
  - Encourage the interview to be dementia friendly – don't send the junior journalist who may feel uneasy about dementia

- Rehearse what is to be said
- **What issues may be covered?**
  - Resource issues
  - Driving
  - Insurance
  - Assistive technologies
  - Election campaigning
  - Media
  - Elder abuse
  - Respite

What is your approach to selection and training of self advocates?

## **6. Champions**

In Australia only one person in public life has disclosed their diagnosis of dementia – Hazel Hawke – wife of former Prime Minister Bob Hawke. Very significant for awareness of dementia. We have of course benefited from the disclosures of high profile people in the USA

What examples do you have?