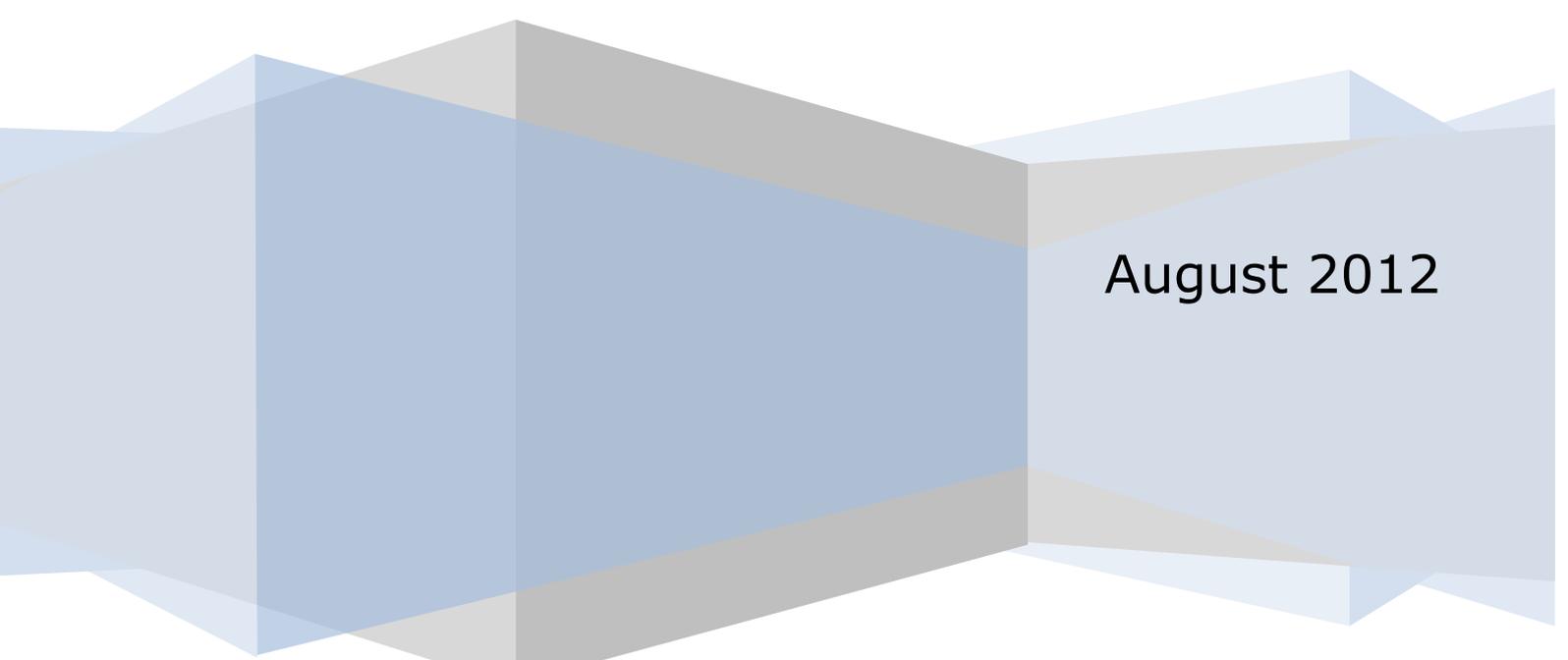


# **Older People's Advocacy: Exploring ties to Wellness, new developments, and alternative models**

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## **Older People's Advocacy: exploring ties to Wellness, new developments, and alternative models**

### **Background**

In March 2006 the Home and Community Care (HACC) Program of the Health Department in Western Australia adopted a 'wellness approach', under which HACC services are encouraged to work with clients in ways that service to prevent loss of independence by focusing on the retention of existing skills and, where appropriate, focus on regaining skills and increasing independence and well-being (Skinner, Clarke, & Cukrov, 2009). While Advocare is funded by the HACC Program, it is not classed as a HACC service provider; however, it has been seen as important that Advocare also embrace Wellness concepts within its provision of advocacy.

This paper was investigates the concepts of advocacy and wellness and how well these concepts mesh within Advocare's model of advocacy. Through this process, Advocare's advocacy will be contextualised and explored along with alternative models of advocacy, with a view towards highlighting new developments and alternative models in the advocacy field that Advocare may be able to incorporate into its work. Finally, this paper also looks at ways of evaluating advocacy in regard to assessing its effectiveness. It was originally suggested that this paper be conducted in the form of a systematic review, as explained by the Centre for Reviews and Dissemination manual (2008), using rigorous search strategies to discover and evaluate printed material on the topic. However, due to several factors, including time constraints, lack of access to articles, and also a lack of literature that focuses specifically on older people's advocacy, this level of rigour was not possible.

### **Search strategies**

While there is a wide range of literature available about advocacy in general and about advocacy specific groups, such as people with disabilities and mental illness, literature which focuses specifically on older people's advocacy is not extensive (Scourfield, 2007; Kitchen, 2010). Literature in this category which is Australian in origin is even rarer.

A Boolean search for relevant information with a publication date after 2000 was conducted using the following information sources:

- Google and Google scholar
- Curtin University Library catalogue
- Proquest
- Social Care Institute for Excellence online
- National Aged Care Advocacy Program (NACAP) funded advocacy agencies members websites

- Community West website, Sector Development section – *Welcome to the WA HACC Wellness Approach*.
- Department of Health and Ageing website

The following search terms were used:

- advocacy review
- advocacy models
- wellness, advocacy, aged care, elder abuse
- advocacy and older people
- advocacy evaluation

A number of relevant journal articles, and reports were found, many of these in the form of ‘grey material’, which are documents in unpublished form. NAN agencies were also surveyed and asked to highlight any relevant Australian articles not already referenced.

As there were few peer reviewed papers available that were specifically focussed on advocacy for older people, as well as the concept of wellness, another search strategy relied on using texts which themselves include some form of literature review, such as Scourfield (2007) and Pearson & Hill (2009)<sup>1</sup>, and also using the bibliographies of these texts and other relevant publications. As I was not able to source many of the original documents, many are reported on as secondary sources. Also, there was not a lot of relevant Australian material relating to advocacy and older people, so much of the research is from the UK and/or relates more to the field of disability advocacy. Grey material has been incorporated where relevant.

Key informants were also contacted and asked for information and input into this paper. In the early stages of the project I spoke to Caroline Horlock from Silver Chain, who is well known in HACC circles to have a lot of experience and expertise in the area of wellness. Advocacy agencies funded under the NACAP were also asked to complete a simple questionnaire asking for information about their advocacy practices in order to provide contextual information for this paper.

## **Format**

This paper is organised in the following sections –

Advocare in context – this section provides some background information about Advocare and the type of advocacy provided by the organisation. Information is also provided about

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<sup>1</sup> This is a research project commissioned by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) undertaken by Jenny Pearson & Associates Pty Ltd to examine the appropriateness, effectiveness and efficiency of the six models of advocacy funded under the National Disability Advocacy Program (NDAP) and to identify key performance indicators that could be used to measure the success of the different advocacy models now and in the future. The research also explored the interactions and linkages between the different models of advocacy, how these feed into systemic advocacy at the state/territory and national levels and how systemic advocacy influences public policy.

the other advocacy agencies in Australia funded to provide advocacy under the National Aged Care Advocacy Program.

Advocacy explained – this section explores the concept of advocacy, highlighting its different forms and key principles, as well as looking at alternative models.

The Wellness approach - This section introduces the wellness approach as adopted by the Health Department of Western Australia's Home and Community Care (HACC) Program and compares and contrasts the core concepts of advocacy and wellness, as described in the literature reviewed in this paper.

Alternative models for development in line with a Wellness approach – This section further explores alternative models of advocacy - self-advocacy and citizen advocacy, which may be adapted by Advocare in line with a wellness approach.

The Professionalisation of Advocacy – This section focuses on issues pertinent to the professionalisation of advocacy, such as training, standards, and ways of evaluating the effectiveness of advocacy.

Potential areas for development – This section explores potential areas for development that have been identified based on information from the literature review.

Resources – This section contains information on resources available to provide further information.

## Advocare in context

Advocare Inc. is a community based not for profit organisation that was established in 2000 to provide independent advocacy and support for the rights of older people and people with disabilities who are receiving or eligible for the government funded community aged care services or residential aged care. Advocare is also funded to assist older people who are being abused by family or friends, or those who are at risk of elder abuse.

Advocare is one of nine advocacy agencies around Australia funded to provide advocacy under the National Aged Care Advocacy Program (NACAP). These agencies form the National Advocacy Network (NAN). As with other members of NAN, Advocare receives advocacy funding from a number of programs other than NACAP. The composition of funding and thus the client groups served by NAN member agencies varies from state to state as a result of the differing funding sources (the different client groups of each agency have been compiled at Table 1 using information available on the individual agencies websites). These advocacy agencies provide free and confidential advocacy and promote the rights and best interests of their specific client groups.

**Table 1: Advocacy agencies receiving funding from the National Aged Care Advocacy Program and their client groups.**

<b>Advocacy Agency</b>	<b>Client Groups</b>
ACT Disability, Aged and Carer Advocacy Service – ADACAS (ACT)	People with disabilities, older people, and their carers, and mental health consumers.
Advocare Inc (WA)	Older people and people with disabilities or their representatives receiving or eligible for HACC, EACH, CACP services or government-funded residential aged care services, or those experiencing or at risk of elder abuse.
Aged Rights Advocacy Service Inc. - ARAS (SA)	Older people, or their representatives, who are receiving or eligible for community based aged care services including community aged care packages; Consumers or potential consumers of services in Australian Government subsidised aged care facilities; or at risk of, or experiencing, abuse by someone they should be able to trust.
Advocacy Tasmania Inc (Tasmania)	People with a disability, older people living in nursing homes or hostels or receiving Community Aged Care Packages or eligible to do so. People in receipt of or eligible to receive HACC services. People with dementia and memory loss wanting assistance to maintain decision making control over their lives. People with a mental health disorder or appearing before the Mental Health Tribunal. People using alcohol, tobacco and other drug services.
CatholicCare NT (Alice Springs)	Provides a diverse range of social services to a range of client groups including older people receiving government funded aged care programs, families, people receiving drug and alcohol treatment, job seekers, and problem gamblers.

Darwin Community Legal Service (NT)	Assists disadvantaged members of the community to protect their legal rights. Generalist community legal service that provides free legal information and advice on most non-criminal matters. Has the following specialist services - Aged and Disability Advocacy, Credit and Debt Legal Service, Disability Discrimination, Family Relationship Centre Legal Advice Service, Free Legal Advice Sessions, Homelessness Legal Service, Welfare Rights, Tenants' Advice Service.
Elder Rights Advocacy (VIC)	Older people (or their representatives) who are receiving an Australian Government subsidised aged care service in Victoria.
Queensland Aged and Disability Advocacy Inc. - QADA (QLD)	People receiving Australian Government aged care services e.g. residential care, EACH and CACP packages; recipients of HACC services; and carers of these recipients. Also have a guardianship team to provide support and advocacy for an adult who has an upcoming hearing at the Guardianship and Administration Tribunal; potentially has a hearing; wishes to have an order of the Tribunal reviewed, or the Tribunal is conducting a review of their order.
The Aged-care Rights Service - TARS (NSW)	Community legal centre that provides non-legal advocacy for the residents of Commonwealth funded hostels and nursing homes and recipients of in-home aged care in NSW, and legal advice and advocacy for residents of self-care retirement villages.

The above advocacy agencies operating under the NACAP Service Charter work to:

- provide information and advice about rights and responsibilities
- support people to be involved in decisions affecting their lives
- assist in resolving problems or complaints in relation to aged care services
- promote the rights of older people to the wider community

As well as the NACAP funding, Advocare also receives funding from the HACC Program to assist HACC clients with service related issues, as well as elder abuse. Advocare also receives funding through the HACC program to assist Aboriginal and Torres Strait Islander clients. Advocare also receives funding from the Department of Communities WA in partnership with the Northern Suburbs Community Legal Centre to operate the Older People's Rights Service, offering legal and social support services to people at risk of elder abuse in the metropolitan area.

A brief questionnaire was sent to the nine NACAP funded advocacy agencies (including Advocare) via email to elicit further background information for this project. Agencies were asked the following questions:

1. What kinds of advocacy does your agency provide? Please tick all that apply and seem most relevant -
  - **Self-advocacy** – advocacy on one’s own behalf
  - **Individual Advocacy** – any advocacy on behalf of an individual
  - **Personal or Professional Advocacy** – trained workers are employed, usually on a short-term basis, to deal with specific problems and to work with an individual until that problem is resolved. Also sometimes described as ‘crisis advocacy’.
  - **Group Advocacy/Collective Advocacy** – advocacy on behalf of a group of people
  - **Peer Advocacy** – advocacy provided by one person for another who is regarded as a member of their peer group
  - **Citizen Advocacy** – advocacy by a citizen who is not paid to provide it, who is independent of human services, and who creates a long term relationship with the person they are advocating for and represents their interests as if they were the advocate’s own.
  - **Systemic Advocacy** – advocacy designed to change the system, or laws, policies, procedures or practices which cause or perpetrate injustice or inequality.
2. How are your advocates trained to provide advocacy, both before their employment with you and after?
3. Has the way your agency provides advocacy changed over the last 10 years? Please explain.
4. In the last 10 years, has the way in which your agency practices advocacy changed based on new models of practice in the advocacy field? Or are you aware of any new practice models that you would like to incorporate in the way you practice advocacy?
5. Have there been any adverse developments in your field that have affected the way in which your agency practices advocacy? (e.g. Changes to policy, legislation, funding, etc.)
6. Do you know if any past reviews (governmental or otherwise) that have occurred for National Advocacy Network agencies?
7. Are you aware of any research or articles written by or about advocacy provided by National Advocacy Network agencies other than the following:

Tsey, K., Morrish, S., & Lucas, A. (1998). Training in Aged Care Advocacy for Primary Health Care Workers in Central Australia: an evaluation. *Australasian Journal on Ageing*, 17(4), 167-171.

Sorensen, H., & Black, B. (2001). Advocacy and Ageing. *Australasian Journal on Ageing*, 20(2), 27-34.

Baker, R., Black, B., & Patience, K. (2000). *Advocating for Clients: Best Choices for Advocacy*. Paper presented at the Carers Respite Conference, Perth.

Cripps, D. (2001). Rights Focused Advocacy and Elder Abuse. *Australasian Journal on Ageing*, 20(1), 17-22.

Five out of the nine agencies responded to the survey and returned the completed questionnaire. The collated responses are described in the following section.

### **Types of advocacy provided**

Four of the five agencies reported that they assisted clients to self-advocate<sup>2</sup>. All agencies also reported that they provided individual and systemic advocacy. Three of the agencies said they also provided group or collective advocacy, with one agency categorising advocacy provided as personal or professional advocacy (which may be seen as a sub-category of individual advocacy), and peer advocacy, which they said they would categorise as third party advocacy which is usually through a family member or friend of the client's.

### **Advocacy training**

This section has been discussed in the relevant context on page 32.

### **Changes in way advocacy is provided**

Agencies were asked if they had noted any changes in the way that they provide advocacy over the last decade. One agency said that nothing had really changed. Advocacy Tasmania reported that they had become more proactive rather than reactive in service delivery, for example, supporting people to make decisions, navigate systems, etc., in ways that prevent problems occurring. This agency has also developed a Dementia Advocacy Service to assist people with memory loss and dementia to maintain decision-making control over their lives through pairing them with a professional advocate who assists them to plan for the future and navigate the care system by providing information, support and advocacy when needed.

Other agencies reported that they have changed the nature of the advocacy they provide from adversarial to a more collaborative partnership approach through establishing links with service providers and the Complaints Resolution Scheme. TARS noted that in recent years they have moved from just responding to issues to providing a more comprehensive service. Three years ago TARS also changed from providing a legal response to aged care issues to providing non-legal advocacy in line with the other NACAP advocacy organisations<sup>3</sup>. TARS also commented on the fact that it is still mostly a telephone service due to the size of New South Wales, which prohibits advocates travelling to rural and remote areas to conduct face-to-face advocacy. However, TARS reports that advocates are using technology more as email has enabled faster responses to letters and contact with service providers and computer-savvy older people and their children. Technology also assists in accessing rural clients through teleconference calls and using Skype to provide more immediate action on concerns.

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<sup>2</sup> The agency that did not specify this may have not have due to the possible ambiguity in the way the question could be interpreted to mean that the agency did not 'provide' self-advocacy. The question was meant to ask if the agencies assisted their clients to self advocate.

<sup>3</sup> In contrast to other NACAP funded advocacy agencies, TARS has always been a Community Legal Centre.

## **Changes in advocacy based on new practice models**

In answer to the question about changes to agency practices based on new models of practice in the advocacy field, three agencies said 'No' or that they were not aware of any new aged care advocacy practice models, although one agency said that they do try to keep informed by looking at information about advocacy from the UK and New Zealand. Advocacy Tasmania mentioned their Dementia Advocacy Service (as discussed above), and QADA reported that they have developed a Guardianship Advocacy Service which supports adults with impaired capacity who are going through the Queensland Civil and Administrative Tribunal (QCAT).

TARS spoke about how the use of new technologies has changed the way they operate (as discussed in the previous section), as well as how they are involved in stakeholder meetings and seminars and provide input into many submissions and reviews. TARS also received a grant from SBS television last year which provided many months of short ads which reached out to potential clients in rural and remote areas of NSW as well as interstate.

QADA reported that they are continually updating their procedures and practices from a continuous quality improvement framework point of view. QADA had developed several helpful practice tools and frameworks including the Guardianship Advocacy Service, a framework for advocating for clients who are ageing with mental health issues which has resulted in the incorporation of a recovery framework model into their advocacy framework. They have also developed an advocacy framework for working with Aboriginal and Torres Strait Islander clients and are in the process of developing one for working with culturally and linguistically diverse clients. QADA have developed a Questionable Capacity Tool (this is based on the *Who Can Decide?* six step capacity assessment process) to assist advocates to determine whether they can take instruction from clients.

## **Adverse developments in the field**

All agencies reported that they had been affected by adverse developments in recent years, with much reference to a lack of funding or funding cuts. Advocare reported that they had been hampered in their development by a lack of growth in funding, and also that this had meant that they are able to do less travel to rural and remote areas than in the past. ARAS commented that there have been adverse developments and that there have been too many to document in the space provided, however they have tried to influence what they can by providing submissions and attending consultations. Advocacy Tasmania stated that funding cuts at the State Government level have affected their agency, and commented that advocacy is vulnerable to cuts or is ignored when new funding and service system expansion is occurring as it is still not well understood or supported by politicians and bureaucrats. QADA also reported that they have had very little increase of funding from the Commonwealth even though demand has increased, and that this has resulted in the modification of their service delivery. They also mentioned that the recent 316 Pay Equity Regulation that came into force in Queensland had meant a restructure of the organisation in order to meet service demands, which has impacted on their ability to provide a quality service.

TARS commented on several adverse issues. Firstly, that aged care facilities seem less accountable for their actions, for example, refusing to refund accommodation bonds, saying they do not fear NACAP service or the Aged Care Complaints Scheme, and refusing to accept new residents who genuinely require care due to different and often acute medical conditions, including dementia and Alzheimer's disease. Secondly, they have lobbied successfully for funding to provide advocacy for HACC clients – all states other than NSW and Victoria had previously received funding to do this work. Thirdly, TARS commented that funding has been inadequate to meet the needs of all NSW care recipients and that funding bodies have not taken into consideration the growing number of aged care residents and clients of community care services in order to fund the agency adequately. Fourthly, changes to the Aged Care Complaints Scheme in the last few years has had a negative effect on the provision of advocacy and has meant that NACAP services have had to comply with legislative changes which promote conciliation of issues and sometimes seem to diminish responsibility of the aged care provider. However, due to some proactive measures on their part, TARS report that there have been changes to the Department of Health and Ageing's website and the Complaints Scheme's brochure that highlight the importance of advocacy and that complainants are able to access an advocate at any stage of the complaints process.

### **Past agency reviews**

Advocacy agencies were asked if they were aware of any past reviews of National Advocacy Network agencies. One agency mentioned it was only aware of the Productivity Commission reviews into the aged care and disability sectors. Another mentioned a November 2000 report by Brian Elton and Associates and a report from March 2006 by the Allen Consulting Group<sup>4</sup>. One agency mentioned that there have been a number of reviews of the National Disability Advocacy Program (NDAP) over the years and that NDAP is currently rolling out a compulsory certification system which means that any agency not certified by December 2013 will no longer be funded. This is apparently having considerable impact on the disability advocacy sector nationally. TARS mentioned that they have undergone accreditation under National Association of Community Legal Centres (NACLC) as a legal centre and that it also receives yearly cross checks under this body, as well as having undergone an independent audit in 2009. One agency commented that NACAP services are not accredited as such, but they feel there is a genuine need for this to occur across all NACAP services.

### **Research and articles about NACAP advocacy agencies**

Agencies were asked if they were aware of any research or articles written by or about the advocacy they provide other than those listed on the questionnaire (at page 8). Three of the agencies said they were not aware of other articles. One agency mentioned several papers they presented at conferences as well as other information from the Office of the Public Advocate in Victoria that was a little dated. Another agency mentioned that they have

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<sup>4</sup> I have been unable to locate these reports.

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*August 2012*

written articles for the *The Standard*, the newsletter for the Aged Care Standards and Accreditation Agency, as well as *The Chronicle*, the newsletter for the Aged Care Association Australia (NSW), and the *Australian Ageing Agenda* on financial exploitation (Tom Cowen and Patricia Joyce, April 2012).

This section has provided some background contextual information about Advocare and other advocacy agencies that provide advocacy for older people. The following section provides more in depth information about the various definitions of advocacy and underlying concepts.

## **Advocacy explained**

Advocacy is a relatively straightforward concept. It has been described in many different ways, but simply put, it is the process of standing up for the rights of another person. In general terms, an advocate takes the side of another person or group of people and represents their rights or best interests (Baker, Black, & Patience, 2000). Many professions act as advocates in the course of their work, including lawyers, human service workers, and union officials.

There are many different ways of practising advocacy and being an advocate. Informal everyday advocacy may involve speaking up on behalf of another person, for example, by saying that another person waiting at the counter to be served was there before you. While legal advocacy practiced in court by lawyers in defence of their clients, lies at the other pole.

Advocacy involves representing and working with a person or group of people who may need support and encouragement to exercise their rights, in order to ensure that their rights are upheld. It may involve speaking, acting, or writing on behalf of another person or group. Advocacy differs from mediation or negotiation in that these processes aim to reach a mutually acceptable outcome between parties. It has no prescribed or clearly determined method. What constitutes advocacy will differ in different circumstances and according to the skills and needs of the individual or group. Advocacy may involve working against established or entrenched values, structures and customs, and therefore needs to be independent of service providers and authorities.

### **Vulnerability**

The concept of 'heightened vulnerability' (Wolfensberger & Thomas, 1983) proposes that members of certain groups, particularly those who are stigmatised, suffer a double disadvantage (Baker et al., 2000). They are firstly seen as disadvantaged through being a member of a stigmatised group, and secondly, because they belong to a group of people that are usually reliant on other people to have their primary care needs met. Advocacy services were developed in the recognition that people who are reliant on others for care are not always in the best position to assert their own rights, and this often dependent relationship between service user and service provider may hold the potential for abuse, neglect, and exploitation (Baker et al., 2000). Effective advocacy plays a role in redressing the imbalance of power that may exist in such relationships (Sorensen & Black, 2000).

Along with the social processes of counselling and mediation, advocacy assists to fulfil common personal needs and empowers us in our struggle for human rights (Craig, 1998). Advocacy is often linked with promoting client-centred services and developing partnerships between professionals, patients, and others (Craig, 1998).

## **Human rights and empowerment**

Advocacy has strong links with the human rights movement and the concept of empowerment, as empowerment is associated with relationships of unequal power and powerlessness (Craig, 1998). In democratic society, it is important that any difficulty in personally exercising rights does not mean that these rights no longer apply (Ronalds, 1989). Underpinning advocacy is a human rights framework and the concept of educating and empowering the older person to take action to protect their own rights and best interests. The keys to successful empowerment include:

- Receiving and understanding information about rights and what constitutes abuse
- Understanding all possible choices and the consequences of those choices
- Having privacy, dignity and the right to undertake risk respected
- Being supported throughout the process
- Receiving support and respect for the decisions they make and the action taken

(Health Canada, 1994)

The human rights-based empowerment approach underlies current responses to aged care and elder abuse advocacy in Western Australia (Black, 2008). This approach provides older people with strategies and choices to overcome their issues (be they service issues or elder abuse) which are tailored to their individual circumstances, with the paid advocate supporting the older person to implement the choices they have made (Cripps, 2001). Empowerment is crucial, especially in the long term, and although it may take time to empower someone who has been abused for a long period, much can be achieved through this process and the older person should not be rushed to suit the needs of the worker or the organisations (Pritchard, 1999). Ideally, as a result of the advocacy process, the person experiencing elder abuse experiences an increase in the power and control they have over their situation and feels more able to assert their rights (Faye & Sellick, 2003). An understanding of the links between human rights and advocacy are important in ensuring that advocacy interventions are empowering.

This section explores the different aims, forms, and definitions of advocacy. It also explores key concepts and principles underlying effective advocacy.

## **Aims and benefits of advocacy**

The common aims of older person's advocacy are to:

- Increase the older person's control over goods and services
- Overcome barriers that restrict opportunities
- Ensure appropriate societal and service delivery responses
- Protect human rights

- Ensure a better quality of life
- Be responsive to and emphasise individual needs and wishes
- Be oriented towards outcomes for older people
- Aim for empowerment of disadvantaged individuals and groups
- Challenge stereotypes and stigma

(Ivers, 1998)

Kitchen (2010, p. 10) proposes that advocacy for older people is likely to have the following benefits:

- Independence from service provision
- Helps those who have difficulty representing their interests
- Helps older people exercise their rights
- Helps older people to express their views and make informed choices
- Puts the interests of the older person first
- Challenges injustice
- Challenges abuse and oppression.

### **Forms of advocacy**

Advocacy can take many different forms. According to Barnes (1998), there are essentially only three types of advocacy – self, voluntary, and professional – though they may take a variety of forms. Examples of the different forms include:

- **Self-advocacy** – advocacy on one's own behalf.
- **Individual Advocacy** –advocacy on behalf of an individual.
- **Personal or Professional Advocacy** – trained workers are employed, usually on a short-term basis, to deal with specific problems and to work with an individual until that problem is resolved. Also sometimes described as 'crisis advocacy' (Weafer, 2003, in Pearson & Hill, 2009, p.11).
- **Group Advocacy/Collective Advocacy** – advocacy on behalf of a group of people.
- **Public Interest Advocacy** – advocacy provided by a worker who is paid to advocate on behalf of others. This category includes lawyers, union organisers, and workers in advocacy agencies.
- **Peer Advocacy** – advocacy provided by one person for another who is regarded as a member of their peer group.
- **Citizen Advocacy** – advocacy by a citizen who is not paid to provide it, who is independent of human services, and who creates a long term relationship with the person they are advocating for and represents their interests as if they were the advocate's own.

- **Systemic Advocacy** – advocacy designed to change the system, or laws, policies, procedures or practices which cause or perpetrate injustice or inequality.
- **Social Support Advocacy** – informal advocacy that can occur through friendship or protégé relationships formed with people who have disability and can include work to improve community attitudes and to improve specific living conditions and services.
- **Interpersonal Advocacy** – direct interactions by family members, professionals or others on behalf of a person

(Westhorp & Sebastian, 1997; Ivers, 1998, Pearson & Hill, 2009)

Pearson and Hill (2009) also describe a range of other advocacy models, including Patient Advocacy, Public Policy Advocacy, Community Advocacy and the Client Support and Representation Model (CSR). However, these forms are not reasonably distinct from the ones mentioned above and may be subsumed under those categories, so they have not been detailed here.

### **Key principles of advocacy**

*...good advocacy is advocacy that is effective in fighting injustices and in advancing the rights of people who are being treated unfairly. Bad advocacy, then, is advocacy that does not really work to advance or safeguard the rights and interests of the people for whom it is intended.*

(Parsons, 1994, p.15-17)

A number of principles that underpin the practice of effective advocacy have been extracted from Cocks and Duffy (1993), Westhorp and Sebastian (1997), Margiotta et al. (2003) and described below.

#### **Participation and inclusion**

Participation and inclusion are key principles of advocacy (Wolfensberger & Thomas, 1983; Cocks & Duffy, 1993; Westhorp & Sebastian, 1997). Participation is considered to be a political right in Western societies (Wolfensberger & Thomas, 1983; Westhorp & Sebastian, 1997), and a goal of empowerment is to enable people to participate in managing their own lives. Participation is both a principle for empowerment and a strategy for achieving it (Baker et al., 2000). It is a principle in the sense that it is morally correct to involve people in decisions that affect their lives, and becomes a strategy for empowerment in the sense that it contributes to the achievement of socially just outcomes (Westhorp & Sebastian, 1997).

There are three overarching principles of good practice for agencies providing information, advice and advocacy to older people that relate to participation and inclusion:

- The involvement of older people in the design, implementation and monitoring of schemes and projects
- The centrality of the older person in all provision of information, advice and advocacy schemes
- The importance of face to face communication

(Margiotta et al., 2003)

### **Vigorous advocacy**

The concept of vigour in advocacy is related to the level of energy applied by the advocate in addressing and promoting the interests of the person they are advocating for (Cocks & Duffy, 1993). The degree of vigour applied often correlates with the strength and effectiveness of the advocacy effort, i.e. greater vigour = stronger advocacy. However, its application to an advocacy effort may be limited by a number of factors, including:

- Lack of knowledge about where vigorous advocacy is relevant and useful
- Lack of insight by the advocate in understanding the wishes and needs of the individual or group
- Lack of resources, i.e. financial, infrastructure, knowledge
- Advocates being employed by organisations which have policies which set them against the interests of, or hinder them in strongly advocating for the vulnerable individuals or groups they are supposedly representing
- Desensitisation of the advocate to the issues of the individual or group for whom the advocacy effort is employed, i.e. the advocate no longer sees the worth of the advocacy effort or is not aware of the significance of the effort to the individual or group it is attempting to assist.
- Lack of ongoing commitment to the advocacy effort.

(Cocks & Duffy, 1993)

It is important for advocates to be aware of potential barriers to the advocacy process and to employ appropriate strategies in order to maintain the level of vigour required in any given advocacy initiative (Baker et al., 2000).

### **Advocacy has commitment (fidelity)**

Effective advocacy can also be linked to the concept of fidelity, or commitment to the advocacy effort (Baker et al., 2000). Advocates generally support people who are vulnerable in some way, and this vulnerability may often require a level of ongoing commitment. This may be due to a lack of continuity in personal relationships, employment, physical environments, and other areas of the person's life. The advocacy is usually more effective if there is a high degree of commitment to providing the advocacy for as long as it is required in

order to address the person's issues or needs. This may also assist in the development of good rapport between the advocate and their client. Fidelity is an essential for effective advocacy as the person being advocated for needs to know that the advocacy effort will be seen through to the end, regardless of how long it takes (Cocks & Duffy, 1993).

### **Advocacy strives to avoid and minimise conflict of interest**

It is important to the provision of effective advocacy to understand the notion of 'conflict of interest'. Conflict of interest may occur when a person or organisation is involved in multiple interests, one of which has the potential to corrupt the motivation for an act in the other, or alternatively as:

*...situations in which two (or more) valid principles clash and cannot co-exist*

(Wolfensberger, 1977, in Cocks & Duffy, 1993, p. 74).

Conflicts of interest may arise at any point in the advocacy process, and if they are not recognised and dealt with, they may have significant impact on the effectiveness of the advocacy effort (Baker et al., 2000). Conflicts of interest may occur between the advocate and the client, and also at the broader systemic level between funding bodies and service providers. It is essential for good advocacy practice for advocates to be constantly aware of the potential for conflicts of interest and to employ strategies to minimise this in the best interests of the client. Strategies may include declaring the conflict immediately, limiting the advocacy effort in some way to minimise the conflict of interest, or organising for an alternative advocate (Westhorp & Sebastian, 1997). If the advocate is independent of both formal and informal organisations or structures, then the potential for conflict of interest is largely minimised, leading to greater effectiveness of the advocacy effort (Baker et al., 2000).

### **Advocacy takes the side of the vulnerable person or group who is disadvantaged**

Advocacy is concerned with power and addressing the power imbalances in society. Generally speaking, the groups or individuals with power are more influential in ensuring that their interests prevail. Advocacy at its most effective makes sure that these power differences are noted and that the side of the most vulnerable and disadvantaged party is recognised and supported. Advocates must be careful not to become compromised by pressure from major stakeholders, and concern themselves instead with establishing an even playing field between the opposing parties by supporting the rights and best interests of the most vulnerable and disadvantaged (Cocks & Duffy, 1993).

### **Advocacy is client-directed and concerned with genuine life needs**

As advocacy is concerned with addressing power imbalances, it encompasses the notion of empowerment. Advocates try to empower their clients by providing information and support to assist them to self-advocate and address their own concerns where possible. It is important for the advocate to empower the client to choose the way in which the advocacy effort will go ahead through the process of providing them with relevant information, support and options.

People who need advocacy support are vulnerable or disadvantaged in some way already, and to exclude them from the process of decision-making about their situation further disempowers them (Baker et al., 2000). Thus, it is essential that clients are enabled to define their own needs. A person's fundamental needs for food, shelter, safety, etc., must be met before addressing the so-called 'higher order' needs such as lifestyle, independence, and fulfilment of wishes – basic needs must be met before other issues can effectively be addressed.

There are often two distinct processes involved in an advocacy effort - one is helping the person being advocated for to gain access to services and benefits; the other is creating rapport and becoming a warm, caring and supporting friend (Ivers, 1998). However, the later is more relevant to the more long lasting relationships involved in a citizen advocacy relationship, and may pose a problem for professional or crisis advocates as it could extend the professional role into something unwieldy that may interfere with commitments to other service users and contractual requirements (Ivers, 1998). In citizen advocacy, a one-on-one relationship or partnership is formed between the older person and the volunteer advocate, which ensures that the advocate focuses on the interests of their partner alone and represents those interests as if they were their own (Margiotta et al., 2003). This is not possible for a professional worker who has the care of many people.

### **Advocacy must be Independent**

Independent advocacy involves a partnership between an advocate and a person who may be feeling vulnerable, isolated, or disempowered. The advocate provides support, information and representation with the aim of empowering their advocacy partner and enabling them to express their partner's wishes to another person or agency on their behalf (Townesley, Marriott, & Ward, 2009). Advocates are not impartial because they work entirely from the perspective and interests of the older person. Their role is to assist older people by representing the older person's wishes.

*Independent Advocacy supports and enables people who have difficulty in representing their interests, to exercise their rights, express their views, explore and make informed choices. Independent Advocacy supports the person regardless of the demands and concerns of other people and bodies. It challenges the causes and effects of injustice, oppression and abuse and upholds human rights.*

(OPAAL, 2008, p. 1).

The necessity for advocacy to be independent has been argued by many (Margiotta et al., 2003, Dunning, 2005; Scourfield, 2007; Townesley et al., 2009; Kitchen, 2010). It has been proposed that the notion of independence is fundamental to the value of advocacy. It is important that there are no conflicts of interest and the advocate is independent of service providers and of the client's family and carers (Margiotta et al., 2003). Smerdon (2009, in Kitchen, 2010, p.11) argues that:

*Independence gives voluntary organisations the freedom to challenge, to be a channel for dissent and a platform for influence often in the face of statutory indifference, and in some cases active resistance.*

The distinction between independent advocacy and advocacy is that:

*...many people advocate for older people...Most frequently these people are family members, friends of carers. In addition many people advocate as part of their professional occupation, for example nurses, social workers and care workers. However these people often have a conflict of interest between the needs of older people and their employers who are often either directly supplying or/and funding the service(s) used by older people and therefore cannot be said to be independent.*

(OPAAL, 2008, p.2)

It is essential that advocates can stand apart from the interests of the 'system' and focus on what the older person wants (Kitchen, 2010). Interviews with older people who have used advocacy services have highlighted the fact that the perception of independence of the advocacy service was vital (Wright, 2006, in Kitchen, 2010, p.11). In another piece of research by Dunning (2005, p. 31), an older participant proposed that:

*Independence is really crucial for the most vulnerable. That is because reluctance to ask for something or even complain is inversely proportionate to helplessness.*

An important part of independent advocacy is that issues are defined by service users, and that advocates should not be restricted to working on just those issues or tasks that funders consider to be important, as:

*Problems and crises in the lives of older people do not fall into neat, service-defined, pigeonholes*

(Mapes, 2009, in Kitchen, 2010, p.12)

It is vital that advocates are not seen to be acting in the interests of any outside body or service provider, and, although advocacy agencies are often funded by other organisations or service providers, government or otherwise, the interests of such agencies should not come before those of the individual client (Kitchen, 2010). Rapaport et al. (2005, in Jenny Pearson & Associates, 2009, p. 12) has suggested that, although funding from statutory sources is vital to advocacy, the funding relationship may pose a threat to the independence of advocacy schemes in challenging public services. It is possible that occasionally an advocate may come into conflict with the funding body through putting the interests of their client first, and this may lead to a misunderstanding of what advocacy providers are trying to achieve (Kitchen, 2010). However, it must be acknowledged that the extent to which state funding does compromise independence is currently unknown and unresearched (Scourfield, 2007). Dunning (1995) has proposed that advocacy projects funded through contracts or service-level agreements with health and social services departments are all too often compromised

in their independence in that the definition of advocacy has been narrowed to suit the views of the statutory agency. In contrast, Bleeker (2002, in Margiotta et al., 2003, p. 28) expresses the view that the funding is necessary and need not compromise the service.

It has been asserted that to prevent any conflict of interest between the advocacy provider and the person needing advocacy support, the most crucial element of any type of advocacy provision is its independence from public bodies (Equality and Human Rights Commission 2008, personal communication, reported in Townsley et al. 2009: 20). In order to fulfil this requirement, it is recommended that all independent advocacy providers strengthen their independence through governance arrangements, such as having management committees which include advocacy users, advocates and other local residents. It is also suggested that placing a duty on public bodies to fund independent advocacy services would prevent public bodies from withdrawing funding from advocacy services critical of them.

Core strategic elements of independent advocacy include:

- Separation of independent advocacy from other forms of direct service provision
- Independent governance
- Independent funding arrangements (i.e. Services are not directly funded by public bodies, but via other indirect means, such as pooled budgets)

(Townsley et al., 2009)

This set of criteria may be seen as the 'gold standard' for defining advocacy services that are truly independent (Townsley et al., 2009).

The Scottish Executive (2000) provides a clearly defined vision of independent advocacy in their guide for commissioners of such services. It states that good independent advocacy services should:

- Be firmly rooted in, supported by and accountable to a geographical community or a community of interest.
- Be constitutionally and psychologically independent of local and national government
- Not be providers of a service and advocates of users of that service
- Be aware there is no one best model and that different approaches are needed.
- Maintain a clear and coherent focus for their work
- Undergo regular and independent evaluation of their work, with financial assistance from commissioners [funders]

## **The importance of Advocacy**

Often older people requiring advocacy are without significant family and friends, or if they have them, the needs and wishes of the older person may be quite different to those assumed by their support network (Ivers, 1998). Advocacy has an important role wherever decisions are made for older people that are supposedly in their best interests without taking their needs and wishes into account (Kitchen, 2010). One example of this may be where older people are pressured by family and health care professionals to move into residential aged care as they get more frail and require more assistance with activities of daily living, although this may not be what they want. It has been argued that the presence of advocacy helps introduce ethical checks and balances into situations where such high-handed decision-making would not otherwise be questioned, as older people may be discriminated against and treated as if they are not capable of making decisions about their own lives (Thomas & Bracken, 1999, in Kitchen, 2010, p.16).

It has been argued that advocacy organisations contribute to the effectiveness and responsiveness of health and social care services, providing input and feedback from clients and ensuring that their voices are heard and acted upon (Kitchen, 2010). Advocates may assist in identifying where systems are not working and identifying obstacles hindering people from accessing services, as well as gaps in provision (Kitchen, 2010). More importantly, advocacy aims to build the capacity of individuals and communities to solve their own problems, empowering them and reducing the need for service intervention (Kitchen, 2010).

It is important to note that advocacy may not be able to guarantee that the outcome of the process will be exactly what is desired by the older person, as this is often outside the final control of the advocate. However, with the advocate supporting the client's voice, there is a better chance that the eventual outcome will have taken the client's views into account (Kitchen, 2010).

## **The Wellness Approach**

*Wellness refers to a state of optimal physical and mental health, especially when maintained by proper diet, exercise, and other habits.*

(Ryburn, Wells, & Forman, 2008, p. 16)

The wellness approach was adopted by the Health Department of WA's Home and Community Care (HACC) Program in March 2006. Under this approach, HACC funded services are encouraged to work with clients in ways that prevent loss of independence through focussing on the retention of existing skills, and regaining skills, where appropriate. It is hoped that this will lead to increased independence and well-being as opposed to continuing or increasing dependence on services being provided by others (Skinner, Clark, & Cukrov, 2009). This approach focuses on building the capacity of both HACC service recipients and their carers (Community West, 2012). The wellness model represents a change from previous ways of working within HACC funded agencies which may be seen as a 'dependency model' where support delivered is task oriented and focused on doing things 'to' or 'for' clients and fostering dependence on services (Community West, 2012). Emerging research and the success of Independence programs has suggested that a service delivery model which is focussed on capacity building through optimising an individual's functional and psychosocial independence may have positive and far reaching benefits for HACC clients (Community West, 2012).

Core components of the wellness approach are (Community West, 2012):

- Capacity building and social connectedness to maintain or promote a client's ability to live as independently as possible with or without HACC support
- A strength based holistic assessment and approach to support that promotes clients' wellness and active participation in goal setting and decisions about their support needs
- Support and planning that can respond to people's goals and are capable or maximising the client's independence
- Support focussed on functional and social goals with a focus on community connections
- Collaborative partnerships between individuals and providers; and between providers for the benefit of clients
- Time limited support as appropriate
- Planned review process and changes to support plans to accommodate progress, including ongoing appropriateness of service

## **The policy context**

The wellness approach (or active service model) is underpinned by the concept of 'successful ageing'. This emphasises the roles of healthy life styles and daily routines, social support, exercise and a sense of autonomy and control in enabling older people to maintain their health and independence for as long as possible (Ryburn et al., 2008). The HACC program, although widely regarded as a highly successful program, has been critiqued in the past as following a 'dependency' model, where insufficient attention is given to an individual's potential or actual capabilities. This may have the effect of prematurely reducing a client's capacity to participate in important physical and social activities, such as shopping and cooking (Ryburn et al., 2008). An important concept within this model is the promotion of 'wellness', which includes good physical and mental health, especially when maintained by healthy diet, exercise, and other habits. This may involve several components, such as health promotion, improvement in activities of daily living, and social participation (Ryburn et al., 2008). An ecological approach to wellness suggests that wellbeing is derived from interaction with a combination of family, community and social relationships, and consequently, active participation within a broad social network has been strongly linked to successful ageing outcomes (Ryburn et al., 2008).

The wellness approach may be seen to empower:

*...the individual to reach their full potential, gain independence, restore healthy relationships and increase community participation functions to prevent the occurrence of elder abuse, while also encouraging positive principles for community organisations that respond to the needs of the elderly.*

(Budd, 2010, p. 12-3)

The wellness approach has been promoted as a strategy to dramatically reduce the risk of abuse through decreasing an older person's dependency and promoting preventative and proactive measures to ageing which may have the consequence of preventing abuse (Budd, 2010). However, to date there have been no published peer reviewed studies that have provided evidence that the wellness approach is useful in preventing elder abuse (Hutchison et al., 2006, in Budd, 2010, p. 11). Nevertheless, Budd (2010) proposes that through assessing existing literature on this approach, it may be established that there is a strong causal link between the aims and goals of this strategy and outcomes in preventing elder abuse at a community level. It has been concluded from the literature that the majority of programs employing a wellness approach as a primary intervention method have focused largely on lower dependency individuals in which there is a limited need for service as functional ability is greater (Budd, 2010).

## **Linking advocacy and wellness**

There is a current movement in health services towards redesigning services around the needs of the patient (Bowers, Bailey, Sanderson, Easterbrook & Macadam, 2007; Kitchen, 2010). Contemporary thinking in health and social services aims to put people first and shape

services around their needs and wishes, making them person-centred, rather than service-led (Bowers et al., 2007; Kitchen, 2010). According to Kitchen (2010, p. 24):

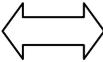
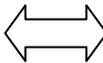
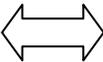
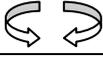
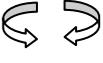
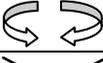
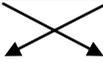
*These are the very values and ideals that advocacy with older people has been seeking to promote from the very earliest days of the movement.*

Wehmeyer, Bersani & Gagne (2000, in Pearson & Hill, 2009, p. 3) propose that the terms self-advocacy and self-determination are often used interchangeably or that one may be viewed as a skills subset of the other. Also, the development of the self-advocacy movement in the United States has been described as occurring during a time where the philosophies and practices of normalisation, inclusion and person-centred planning had emerged (Pennell, 2001).

From the literature reviewed for this paper, it appears that advocacy (as practiced by Advocare) and wellness (as espoused by the HACC Program) share several core concepts, which are listed in Table 2 below. Firstly, they are both seen as being client centred and as working towards assisting clients to strengthen their social networks. The advocacy concept of empowerment may also be linked to the wellness concept of capacity building. Independence is important to both; however, in terms of advocacy it is the independence of the agency which is important, while for wellness, the independence of the client is the focus. Both frameworks support people – for advocacy it is people who are vulnerable in some way, which may encompass a range of levels of functionality. For wellness, it is people needing assistance, and this is generally people with lower levels of dependency in relation to service provision. These categories may sometimes overlap, as someone deemed vulnerable may or may not require services and vice versa. There are also several concepts which do not quite mesh, for example, advocacy is rights-based, an abstract global concept, while wellness is strengths-based, which is specific to the individual. Also, advocacy provided by Advocare is usually short-term and issue-specific, while services provided by HACC services are generally longer term.

Given this comparison, it may be concluded that the advocacy and wellness approaches share several core concepts and that there are links between others; however, there are some essential differences. This is perhaps to be expected given the different nature of the services being provided, as Advocare is an advocacy agency, not a HACC service. Advocare is in a different position from HACC services as it is not focussed on a long term relationship with a client, rather short term, usually crisis, intervention and advocates generally do not receive feedback to know if the outcome of the advocacy has assisted the client to improve independence or well being. Advocare is also not in the position to observe and measure the side benefits of the advocacy process.

**Table 2: Comparison of core concepts of Advocacy and Wellness**

<b>Advocacy</b>		<b>Wellness</b>
Client centred and client directed - Participation and inclusion		Client centred and self directed - Autonomy and control over affairs
Assists clients to identify strengths in their social networks		Strengthens and encourages active participation in social network
Empowerment - Self-advocacy		Capacity building
Independence of agency		Independence of client
Supports vulnerable people - Range of levels of functionality		Supports people needing service assistance - Focus on lower dependency individuals
Rights-based approach		Strengths-based approach
Short term		Time limited - but usually longer term

### **Wellness: Key features and strategies**

Community West (2012) has identified a number of key features/strategies in order to assist HACC agencies to implement a wellness approach. They can be categorised into two broad areas, organisational and service delivery, which have the following features:

#### **Organisational**

- Changing the mind set of all stakeholders, i.e. management, staff, volunteers clients and their families, about the views they hold in relation to the capacity of older people and people with disabilities to improve in their functioning;
- Building staff awareness, skills and confidence to promote the wellness approach;
- Undertaking staff training in the principles of the wellness approach and how to undertake assessments and develop client support plans using the approach.

#### **Service Delivery**

- Looking at the reason behind the request for assistance or change in support instead of just providing services or increasing services;
- Undertaking ability-based assessments and support plans;
- Undertaking goal planning in partnership with client;
- Undertaking time-limited interventions and services;

- Client and carer education in principles of optimising function and well-being;
- Regular reviews and changes to support plans to accommodate progress,
- Including looking at the appropriateness of continuing service;
- An emphasis on social networks and community connections to link clients back to their communities;
- At the end of service, looking at the appropriateness of connecting clients with mainstream community programs /services.

(Community West, 2012)

These may have limited applicability to Advocare due to the different nature of the services being provided, but should be considered and measured against current practices if the organisation wishes to ensure a wellness approach is implemented as far as possible.

## **Alternative models for development in line with a Wellness Approach**

The background and core concepts of the wellness approach adopted by the WA HACC Program were discussed in the previous section. This section focuses on models of advocacy (alternative or otherwise) that may be pursued or finetuned by Advocare that seem to best fit within a wellness approach.

The wellness approach emphasises capacity building and encouraging client self-determination and control over affairs while also encouraging active participation in social networks. To this end, it appears that self-advocacy and citizen advocacy are perhaps a better fit to a wellness approach than individual or professional advocacy. These two forms of advocacy will be further explored in the following section. However, it must be stressed that there is no one size fits all approach to advocacy and it is important that a range of approaches are available.

### **Self-advocacy**

Self-advocacy has been described as a process of empowering people to take control over their own lives in order to make decisions and take the consequences (Pennell, 2001). Through the self-advocacy process, individuals are empowered through the provision of information, advice, and support to advocate on their own behalf. Pennell (2001) describes the evolution of the philosophy of self-determination as a result of social movements including disability rights and self-advocacy. Self-determination is:

*... a call for shifting power from the system to the individual, allowing people to choose how they live and to be supported in ways that facilitate their preferences.*

(Pennell, 2001, p. 1)

Pennell (2001) suggests that there is no one perfect approach to self-determination, as it is the simultaneous combination of many components, such as self-awareness, independence, education, choice, reflection, evaluation, self-advocacy, and community based activities. Self-advocacy is entirely compatible with the wellness approach and it is a strategy already used by Advocare to empower their clients through the provision of information and support. However, it is worth questioning whether this could be taken a step further through a more formal process. Fendorak and Griffin (1986) developed a self-advocacy program to assist older people to speak up for themselves and maintain control of their own health and lives. This program was found to be effective in helping older people take increased initiative and control, develop a cohesive support network, and provide input into program planning. Advocare might like to explore developing a similar program as a more pro-active method of assisting their client group to foster their self-advocacy skills.

The evolution of self-advocacy has been a vital part of the movement toward self-determination (Pennell, 2001). However, there are some barriers to self-advocacy that may limit its effectiveness, including:

- lack of experience among self-advocates
- continued lack of support by the community as a whole
- a lack of leadership skills
- lack of funding resulting in insufficient monetary resources to adequately access and prepare consumers for self-advocacy and to implement consumer choices expected to arise as a result of self-advocacy, also meaning that representatives are not able to attend national meetings
- service provider attitudes
- family attitudes
- consumer characteristics such as cognitive, communicative and motivational deficits that may impair their ability to understand their rights, engage in competent decision-making and advocate on their own behalf
- lack of public awareness of self-advocacy and self-advocacy groups
- community antipathy towards self-advocacy (e.g. having to convince family members and caregivers that self-advocacy is worthwhile and a non-threatening concept)
- loss of key members
- personal conflicts between group members
- maintaining motivation, interest and concentration
- transport difficulties resulting in reduced attendance at meetings
- overbearing advisors or dependence on advisors

(Pennell, 2001; and Bramley & Elkings, 1988; Wolfe, Ofiesh & Boone, 1996; both in Pearson & Hill, 2009, p. 14-5).

A number of studies in disability advocacy have identified the effectiveness and benefits of teaching self-advocacy skills (Test et al., 2005; Pocock et al., 2002, both in Pearson & Hill, 2009, p. 13). It has been proposed that teaching people the skills of self-advocacy results in improvements to self-esteem and self worth (Seymour & Peter, 2004, in Pearson & Hill, 2009, p. 13). However, a conflict exists in the concept of self-advocacy, where advocacy is defined as acting in the interests of or on behalf of *another* person or group. Also, Cocks and Duffy (1993) raise concerns that vulnerable people with disability may be placed in situations of increased risk if they are encouraged to challenge powerful interests without adequate support.

## **Citizen Advocacy**

Citizen advocacy is another form of advocacy which it may benefit Advocare to consider including in its range of advocacy approaches. Citizen advocacy uses trained volunteer advocates who engage in a one-to-one partnership with a vulnerable person who is unable to exercise their rights and so needs someone to speak on their behalf (Margiotta et al., 2003). In the UK it appears that the citizen advocacy model has been the main type that has grown and developed in relation to older people (Thornton & Tozer, 1994, in Margiotta et al., 2003, p. 25). While some UK advocacy schemes are generic and relate to people living within certain areas, others are specific to older people or people with mental health problems or learning difficulties (Williams, 1999, in Margiotta et al., 2003, p. 25). Margiotta et al. (2003, p. 28-31) provides a list of examples of UK citizen advocacy projects using trained volunteers and proposes the following principles:

- Allegiance: the advocate must be loyal to the partner alone in order to truly represent that person's interests.
- Unpaid: the citizen advocate is a volunteer who is giving this service because of their desire to help, not because of being paid. This links with being independent of an employer who may have different considerations about the care and future of the older person.
- Long-term: Whenever possible the partnership between the older person and the advocate should be seen as long-term. Time is needed to get to know the partner and to understand their needs and wishes.
- Diversity: Citizen Advocacy should recruit and use volunteers from a variety of backgrounds, age and experience. In some schemes many of the volunteers are older people.

(Margiotta et al., 2003, p. 41-2)

A strength of the citizen advocacy model is its ability to independently represent the interests of individuals:

*The Citizen Advocacy Office's lack of control over advocates, which some people find so disturbing, establishes a power in individual advocates that no advocate who was paid, or licensed, or a mere agent carrying out directions of a Citizen Advocacy Office, could possibly have.*

(Ward, 1986, in Pearson & Hill, 2009, p. 7)

It has been noted that citizen advocacy has been very successful in Australia and is an efficient way of providing stable advocacy to people over a long period of time; however, it is currently used more in relation to people with disabilities. It may be worth exploring how the citizen advocacy model may be adapted to assist clients of Advocare who lack family or friends to represent their interests and may require more long term advocacy support. Seymour & Peter (2004, in Pearson & Hill, 2009, p. 19) suggest that 60 motivated and articulate citizens would be able to provide far more advocacy over the long term than one

paid worker. Martin (2003, in Pearson & Hill, 2009, p. 19) conducted a study of Illawarra Citizen Advocacy and concluded that a high-functioning citizen advocacy program can lead to more advocacy dollar for dollar than even the most conscientious paid advocacy.

### **Professional versus voluntary advocacy**

There is some debate about whether voluntary or professional advocacy provides the most effective outcomes. The need for an advocate to have absolute independence has been emphasised by social theorists and they believe that the many constraints within which professionals commonly work, such as the need to follow agency procedures, to satisfy a manager/funding body that this is a good use of their time, and to remain credible with colleagues, may impinge on their effectiveness (Ivers, 1998). If the advocacy work involved challenging an employer or a colleague, it may be very difficult for them to pursue the case with absolute vigour. As discussed in the previous section on advocacy, it has been proposed that to prevent any conflict of interest between the advocacy provider and the person needing advocacy support, the most crucial element of any type of advocacy provision is its independence from public bodies, and citizen advocacy fulfils this requirement.

Hunter and Tyne (2001, in Pearson & Hill, 2009, p. 19) argue against the professionalisation of advocacy:

*The move to regularise, accredit, train, approve and legitimise advocacy for selected eligible service clients is a bureaucratic response to the ungovernable nature of community...Bureaucratic beliefs that citizen advocacy played to its own well-developed rules is 'too difficult', 'takes too long', 'doesn't perform', have led to schemes discarding many of their own carefully-developed safeguards, and adopting instead the processes and procedures of the world of professional services. As they do, they become less capable of delivering what citizen advocacy set out to do: long-term, freely give, independent relationships with offer the possibility of belonging to a network of community connections.*

However, Ward (1986, in Pearson & Hill, 2009, p. 19) calls for a range of advocacy programs or types:

*With the legal system having its limitations, and citizen advocacy its inefficiencies, what is needed is a range of advocacy programs or types. John O'Brien comments that the success of a Citizen Advocacy program may depend on whether other forms of advocacy exist in a community.*

It has been suggested that citizen advocacy should not stand alone, but exist in conjunction with many different styles of advocacy. These include group advocacy programs, self-advocacy groups, ombudsmen at state and federal levels, the human rights commission, and lawyers and specialised legal services, with the Citizen Advocate being able to seek assistance from these programs and vice versa (Ward 1986, in Pearson & Hill, 2009, p. 19).

## **The Professionalisation of Advocacy: Training, Standards, and Evaluation**

While advocacy may be practiced by anyone, trained or untrained, it has been seen as necessary for the practice of advocacy in a professional capacity that advocates (paid or otherwise) undergo some kind of training and evaluation. The following section discusses issues related to the professionalisation of advocacy, such as training, standards, and evaluation, and incorporates information from the survey of NACAP funded advocacy agencies that was reported on earlier in this paper (see pages 6-12).

### **Advocacy training**

In the survey of NACAP Advocacy agencies sent out in relation to this project, agencies were asked how their advocates were trained to provide advocacy, both before and after their employment. In response, all agencies mentioned that when employing new advocates, they looked for people from a range of relevant backgrounds, for example, people with human or community services qualifications, training and experience in advocating for others or working in the aged or disability sector. Some agencies mentioned that there is little appropriate pre-employment training available for advocates, and that some employees may have completed advocacy modules as part of a Community Services Certificate or diploma training.

According to the questionnaire responses, the majority of advocacy training seems to occur after employment through completing related courses provided by industry educators, for example, one agency mentioned that the Public Interest Advocacy Centre in their state provides one and two day training courses in various subjects including systemic and community advocacy and human rights, and managing challenging situations, etc. Another agency mentioned that they provide mediation training as a useful skill for negotiating outcomes. Other agencies mentioned that new advocates also receive on the job training through becoming familiar with the policies and procedures manual and also exposure to the experienced advocates they work with, in that they are able to discuss cases with their co-workers and receiving advice and feedback.

How advocates should be prepared and trained is a matter of some debate across the advocacy literature. The Department of Health in the UK has developed a national advocacy qualification<sup>5</sup>. Scourfield (2007) discusses this and expresses some reservations about the professionalization of advocacy. Dunning (2005, p. 88) has proposed in regards to citizen advocacy that it:

*...is not the business of citizen advocacy projects to produce experts.*

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<sup>5</sup> Information about the UK national advocacy qualification is available at: <http://www.advocacyresource.org.uk/National-Advocacy-Qualification>

According to Dunning (2005), it is for the individual advocacy projects to draw up their own programs in terms of the values, knowledge and skills considered desirable. Atkinson (1999, in Scourfield, 2007, p. 23) comments that advocacy seems to work best when there is a trained, supported and managed advocacy workforce. In her review of advocacy, she found that most advocacy agencies stressed the importance of careful selection, initial induction and training, as well as on-going training events. The advocacy training programs may include such elements as:

- What is advocacy?
- Principles and values of advocacy
- Role of advocacy
- Role of Advocates
- Good communication and listening skills
- Disability equality training
- Welfare benefits
- The law and relevant legislation
- Role of services

(Atkinson, 1999, in Scourfield, 2007, p. 23).

### **Advocacy standards**

As part of the professionalisation process, some advocacy projects require their advocates to sign up to a code of practice. A 10 point code has been suggested to secure the rights of people represented by advocates, and this is described in Dunning (1995, in Ivers, 1998, p. 30). The code recognises the role of any known relatives and people providing services, while maintaining the independent status of advocates.

It has been proposed that, with its various forms and different heritages, advocacy needs to work towards achieving commonly agreed standards for good practice and measuring quality (Margiotta et al., 2003; Dunning, 2005; OPAAL, 2006; Scourfield, 2007). In the UK the Older People's Advocacy Alliance<sup>6</sup> (OPAAL) have argued that their network of older people's advocacy services would benefit from an umbrella organisation (OPAAL, 2006), and Margiotta et al. (2003) have proposed that both national standards and codes of practice should be established. Dunning (2005) comments that there have been a number of initiatives to create or contribute to the development of effective advocacy services, however few of these are specific to older people's advocacy. These initiatives include (from Dunning, 2005, p. 55):

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<sup>6</sup> The Older People's Advocacy Alliance (OPAAL) UK is an alliance of advocacy schemes and national and local organisations of older people and for older people. Its aims are the promotion and development of independent advocacy services with older people; and the establishment of standards and quality frameworks for the delivery of such advocacy. Website - <http://www.opaal.org.uk/>

- Advocacy charters (Advocacy Across London, 2000)
- Codes of practice (United Kingdom Advocacy Network, 1997; Barnes et al., 2002)
- Evaluation tools (Hanley and Davies, 1998)
- Training programmes (Brooke and Harris, 2000).

### **Assessing the effectiveness of advocacy**

Advocacy evaluation is an emerging field of inquiry driven to ensure accountability to funding bodies as well as promoting organisational learning (Whelan, 2009, in Pearson & Hill, 2009, p. 21). Concerns have been expressed about the effectiveness of advocacy in the disability sector, and some of these may also be relevant to advocacy with older people. Criticisms include:

- Inadequate strategic planning
- Unclear definition of the desired endpoint
- Failure to integrate issues into a larger social context
- Underfunding and understaffing
- Lack of shared issues amongst the disability community, beyond the general issues of access and equity

(Pearson & Hill, 2009, p.11)

However, there are many methodological challenges to evaluating advocacy, and these include:

- The complexity of public policymaking
- The role of external forces and conditions
- Problems of attribution
- The long time frame needed for changes to occur
- Shifting strategies and milestones
- The low capacity and interest in evaluation from advocacy organisations

(Whelan, 2009, in Pearson & Hill, 2009, p. 21)

Also, the outputs of advocacy are not easily measurable or comparable (Martin, 2007). Hussein et al (2006, in Pearson & Hill, 2009, p. 21) has acknowledged:

*Such complexities are mainly due to the difficulties in establishing cause and effect of advocacy interventions and outcomes as well as the difficulties in defining and agreeing an 'outcome' or its desirability. In complex human systems, where advocacy usually operates, it is difficult to establish which part of the process has caused a specific impact.*

Research with older people has shown a low level of awareness of advocacy services and a lack of understanding of the concept of independent advocacy (Townesley et al., 2009, p. 12). Townesley et al. (2009) reviewed and evaluated evidence about the need, the benefits and the costs associated with independent advocacy. They propose that there is an important distinction to be drawn between benefits from the process of independent advocacy and the benefits resulting from the outcomes of this process. The research reported in the review also found that the outcomes from advocacy may not always be perceived as benefits, even where the process of advocacy is seen as positive by those involved (Townesley et al. 2009). Research exploring the benefits of advocacy for vulnerable adults who had been victims of abuse showed that in the majority of the cases reviewed the goals of the advocacy were met and the abuse was stopped, however, this research was from the perspective of the advocates, not the service users (Townesley et al. 2009:13).

The only research I was able to find that connected wellness and advocacy was a study about improving the propensity for mental health patient self-advocacy through Wellness Recovery Action Planning (Jonikas, Grey, & Copeland et al., 2011). In this study, higher self-advocacy was associated with greater hopefulness, better environmental quality of life, and fewer psychiatric symptoms. Studies have found that patients who actively seek health information, openly communicate with health care providers, and express treatment preferences have better information to inform their decision-making, greater desire to engage in services and treatment and fewer symptoms (Adams & Drake, 2006; Charles, et al., 1997, Loh et al., 2007; Stewart, 1995; all in Jonikas et al., 2011, p.2). While barriers to effective patient self-advocacy include feeling hopeless, having high levels of emotional distress or symptoms, perceiving a power imbalance, and fear of challenging a provider or wasting his/her time (Brashers et al., 1999; Ciechanowski et al., 2003; both in Jonikas et al., 2011, p. 2). The Jonikas et al. (2011) study measures the impact of peer-led mental illness self-management education of self-advocacy among people receiving public mental health services, as well as exploring relationships between self-advocacy and other key recovery outcomes. The study found that among those participants who received the peer-led self-management intervention Wellness Recovery Action Planning (WRAP), greater patient self-advocacy was related to having hope for the future, better environmental quality of life, and being less bothered by psychiatric symptoms. This finding reflects the positive relationship between patient self-advocacy and improved service engagement and client outcomes (Jonikas et al., 2011).

The only piece of research specifically concerning an Australian older person's advocacy agency that has come to light is the study by Cripps (2001) which looks at the effectiveness of the rights focused advocacy model in supporting older people to overcome situations of elder abuse. This study examined 100 case records from the Aged Rights Advocacy Service (ARAS) retrospectively, which represented approximately 20% of total clients over an 18 month period. The study found that the rights focused advocacy model enabled older people to take steps to stop abuse in 50% of those situations and to take action in 34% of situations. No change was recorded in 16% of cases, however, this category was comprised of people who did not wish to progress their case beyond the initial contact phase. Importantly, the

study shows the choices older people make for themselves about which interventions are useful to them, be it informal, formal, or protective network. The paper highlights the critical role an older person's informal network can play (Cripps, 2007).

An evaluation of ten advocacy projects providing services to developmentally disabled and mentally ill persons in the United States found that:

- Negotiation not litigation was the strategy of choice among the advocacy projects
- The use of negotiation resulted in the most favourable outcomes
- Although the advocacy activities did not, as a rule, involve litigation, the presence of a lawyer on the staff or in the network of the advocacy agency enhance the project's effectiveness
- The most expensive activities performed by advocates were administrative actions and investigation
- Referral was the least expensive service per case
- The advocacy agency personnel wage rates and non-personnel costs were especially low when compared to other legal and human service agencies

(Bradley, 1983)

Bradley (1983) concluded that more research needs to be conducted into the process and outcomes of a range of advocacy interventions. She also proposed that a single funding source would result in the maximum stability and coherence for advocacy services, and that advocacy services should be legitimised in state statute and/or regulation.

Further research is needed to investigate the variables that affect both the process and outcome benefits of independent advocacy, so that the factors determining the effectiveness of advocacy intervention are clearly understood. The Townsley et al. (2009) review highlighted that the nature of the advocacy role (including the tasks which advocates undertake) is an important variable in bringing about benefits for disabled people. The evidence showed that there are certain factors which appear to promote the process and outcome benefits, including:

- A relationship built on trust and developed over time
- Credibility and 'clout' with other providers
- Acting as an educator, mediator and campaigner
- A clearly defined role which includes a number of key components relating to specific (and specialist) skills, knowledge and experience.

Further research is required to consider these and other significant variables in any assessment of the effectiveness of independent advocacy (Townsley et al., 2009, p. 16).

There have been a number of evaluation frameworks developed and reported in the literature, mostly in regard to disability advocacy schemes, however, some may be adapted to fit the aged care advocacy sector. Rapaport, Manthorpe, Moriarty, Hussein and Collins (2005, in Pearson & Hill, 2009, p. 22) found that the main measures used to monitor advocacy services in the UK were:

- Reliance on reputation
- Instituting an audit
- Assessment performance against the funding contract
- Holding regular reviews
- Reading the advocacy organisation's annual report

Rapaport et al. (2005) examined several models of advocacy evaluation. A summary of their findings appears in Table 2 (adapted from Rapaport et al., 2005, and developed by Pearson & Hill, 2009, p. 23-4). Rapaport et al.'s (2005, in Pearson & Hill, 2009, p. 22) research identified the following evaluation tools:

- Citizen Advocacy Program Evaluation (CAPE): Specifically designed for the Citizen Advocacy model. Coordinators are interviewed and a rating scale is used to score standards. This has the advantage of linking principles to practice, however, funding patterns may compromise principles.
- Priority Quality Assurance System (PQASSQ): a generic self-assessment tool described as measuring a comprehensive range of operational systems against key indicators. Disadvantages reported were its self-assessment approach and systems focus.
- Community Legal Service Quality Mark (CLSQM): designed for law centres and similar agencies providing representational advocacy, focused on the existence of systems, procedures and working practices rather than outcomes. Reported to have the advantage of providing a level of independent scrutiny but considered cursory by some as it uses a tick-box approach and does not measure the impact/outcomes of advocacy.
- ANNETTE: uses tables to count the number of tasks undertaken, the time taken to complete the tasks and the nature of the different advocacy roles. Considered to be more suited to representational advocacy rather than long term citizen advocacy partnerships.

- Evaluation model devised by the Scottish Executive and promoted by the Advocacy Safeguards Agency: identifies core criteria applicable to the evaluation of all forms of advocacy and specific criteria related to particular case scenarios. Spells out the advocacy process, scope of the evaluation, who should be involved and promotes regular independent evaluation, self-monitoring and regular meetings between funder and advocacy agency to agree evaluation criteria. One complaint was that service users with learning disability could not understand the set evaluation questions and were therefore unable to participate effectively in the evaluation.

**Table 3: Summary of Evaluation Models (adapted from Rapaport et al., 2005, by Pearson & Hill, 2009, p. 23-4)**

Model	Process	Advantages and Disadvantages
<p>Citizen Program (CAPE)      Advocacy Evaluation</p>	<p>Coordinators are interviewed CAPE uses rating scale to score standards.</p> <p>Standards include:</p> <ul style="list-style-type: none"> <li>• Independence of the scheme</li> <li>• Loyalty of advocates to their partners (protégés)</li> <li>• Centrality of relationship between advocate and protégé</li> <li>• Must not resemble a care service</li> </ul>	<p>Advantages:</p> <ul style="list-style-type: none"> <li>• Links principles to practice</li> <li>• Objective measure against set of constant standards</li> <li>• Develops advocacy culture</li> </ul> <p>Disadvantages</p> <ul style="list-style-type: none"> <li>• Funding patterns compromise principles</li> <li>• Only applicable to Citizen Advocacy schemes</li> <li>• Unable to measure impact of the advocacy scheme</li> </ul>
<p>Citizen Information and Training (CAIT)      Advocacy and</p>	<p>Advocacy partnerships (8) and staff are interviewed by a CAIT evaluation team.</p> <p>CAIT investigates:</p> <ul style="list-style-type: none"> <li>• Range of clientele</li> <li>• Advocacy roles</li> <li>• Advocate preparation</li> <li>• Advocate loyalty to partners</li> </ul>	<p>Advantages:</p> <ul style="list-style-type: none"> <li>• As for CAPE</li> <li>• Acknowledges local issues</li> <li>• Provides technical information and reports</li> </ul> <p>Disadvantages:</p> <ul style="list-style-type: none"> <li>• Problems of evaluating partnerships</li> <li>• Barriers to data created by confidentiality</li> <li>• No sense of overall impact</li> </ul>
<p>ANNETTE (devised by Newcastle Council for Voluntary Service)</p>	<p>Focuses primarily on outcomes rather than principles.</p> <p>Uses tables to count::</p> <ul style="list-style-type: none"> <li>• Number of tasks</li> <li>• Time taken</li> <li>• Different advocacy roles</li> </ul>	<p>Advantages:</p> <ul style="list-style-type: none"> <li>• Can be used in a range of advocacy schemes</li> <li>• Measures process and benefit</li> <li>• Allows for comparison between advocacy schemes</li> <li>• Meets contract objectives and is liked by funders</li> </ul> <p>Disadvantages:</p> <ul style="list-style-type: none"> <li>• Potential to overlook subtle success</li> <li>• More suited to casework advocacy than long-term Citizen Advocacy partnerships</li> </ul>

Model	Process	Advantages and Disadvantages
Citizen Advocacy Lincolnshire Links (CALL) - evaluation of CALL's citizen advocacy project for young people	<ul style="list-style-type: none"> <li>Adapted form of CAPE-revised was used</li> <li>Coordinators and additional staff were interviewed</li> <li>Psychological testing of advocates using MMPI-2 and comparative measures</li> <li>Sample of partners (protégés) were interviewed</li> </ul>	Advantages: <ul style="list-style-type: none"> <li>Use of adapted CAPE-revised provided organisational context</li> <li>Used multiple methods for validity</li> <li>Project team and staff involved in shaping the evaluation</li> <li>Recognised importance of personality characteristics of advocates</li> </ul> Disadvantages: <ul style="list-style-type: none"> <li>Learning disability clientele not interviewed</li> <li>Time-consuming nature of psychological intervention</li> <li>Poor response of funders</li> </ul>
Dementia service self-evaluation	Devised questionnaire in consultation with advocacy network.  Questionnaires were sent to carers and professionals in contact with the advocacy project. The questions investigated: <ul style="list-style-type: none"> <li>Awareness, understanding of and access to the service</li> <li>Quality of advocacy and its effects e.g. impact of advocacy on the service user</li> <li>Interviews (planned)</li> </ul>	Advantages: <ul style="list-style-type: none"> <li>Scope of questionnaire</li> <li>Obtained useful data</li> </ul> Disadvantages: <ul style="list-style-type: none"> <li>Poor response to questionnaire (30%)</li> <li>Service users declined to be interviewed</li> </ul>
RETHINK (mental health service)	Used 3 methods (questionnaire, structured interviews, focus group interviews)  Structured interview administered by trained and paid service users was found to be the most effective and cheapest means of evaluation.	Advantages: <ul style="list-style-type: none"> <li>Engaged service users</li> <li>Cheap and easy to implement</li> <li>Meets funders' objectives</li> </ul> Disadvantages: <ul style="list-style-type: none"> <li>May not be appropriate for people with cognitive impairment, particularly where the impairment is severe</li> <li>Absence of standardisation and evaluator independence</li> </ul>

Rapaport et al. (2005, in Pearson & Hill, 2009, p. 24) conclude finally that advocacy outcomes are difficult to measure due to the range of advocacy schemes and their different aims and objectives.

Self-advocacy may be assessed using Brashers' Patient-Self-Advocacy Scale (PSAS), an instrument designed to measure a person's propensity to engage in self-activism during health care encounters (Brashers et al., 1999, in Jonikas et al., 2011, p. 4). The PSAS has been found to correlate well with self-advocacy concepts such as the desire for autonomy in decision-making, the preference for receiving information, and desired level of behavioural involvement (including self-care and active treatment participation) in clinical encounters.

Hussein et al. (2006, in Pearson & Hill, 2009, p. 25) find that the most frequent means by which UK advocacy schemes surveyed in the 2006 study are evaluated is through service level agreements (73 per cent), receipt of an annual report (54 per cent), discussions with staff/volunteers (39 per cent), discussions with service users (39 per cent), and/or discussion at partnership board (39 per cent). Audits of the advocacy service, reference to complaints/compliments, and/or formal discussion with service user representatives are used to monitor 27 per cent of the advocacy schemes. Accredited evaluation tools are used in only 6 per cent of the advocacy schemes.

Hussein et al. (2006) conclude that local authorities that fund advocacy schemes rely on information provided by the advocacy schemes themselves and do not generally have systems in place to interrogate this information or to evaluate whether outcomes are achieved.

Participants in the Hussein et al (2006, in Pearson & Hill, 2009, p. 25) study recommend that advocacy evaluation mechanisms should:

- acknowledge the differences between types (models) of advocacy
- differentiate the role and features of specific (specialist) and generic advocacy schemes
- consider both the process and outcomes of advocacy schemes
- be flexible and not too rigid or controlling
- include the views of people who use the advocacy service.

There is a large amount of further information on advocacy evaluation available in the Pearson and Hill (2009) report, including information on emerging evaluation models such as the 'composite logic model' of evaluation, and the development of standards and performance indicators.

### **Benefits of advocacy**

It has been noted that, though there are examples of service changes resulting from advocacy by individuals and user groups, the greatest impact of self-advocacy seems to have been at the personal level with group members reporting gains in confidence, assertiveness and communication skills (McNally, 1999, in Pearson & Hill, 2009, p. 13).

Advocacy has benefits of both process and outcome. Or put in another way, advocates have both an instrumental and expressive role to play (Scourfield, 2007). Advocacy may help

those who have difficulty representing their interests, help people exercise their rights, help people express their views and make informed choices, and challenge injustice, abuse and oppression (Kitchen, 2010). However, it would be wrong to judge advocacy on the basis of whether or not the client has achieved their desired goal, since this is not necessarily within the advocate's power (Kitchen, 2010). It seems to be recognised that the support provided by advocacy is regarded positively, even where the desired outcome has not been achieved (Townesley et al., 2009). Two main identifiable sets of outcomes experienced by older people as a result of the advocacy process have been found. Firstly, outcomes relating to material or tangible benefits, and secondly, outcomes attached to feelings and emotions relating to self-worth, esteem and confidence (Wright, 2006, in Scourfield, 2007, p. 21). It has therefore been proposed that the fact of having an advocate is as important for older people as the end benefits that having an advocate might bring (Margiotta et al., 2003, in Scourfield, 2007, p. 21) For all that, outcomes are important too, and by helping the client be heard, it is more likely that their desired outcome will be achieved (Kitchen, 2010).

## **Potential areas for development**

Several potential areas for development have been identified based on information from the literature review conducted in relation to this project. In order to pursue the following suggestions, it may be necessary for Advocare to secure some form of extra funding, or if this is not possible, consider forging strong alliances with organisations that provide services similar to those suggested.

### **Increasing profile and accessibility**

There are many reports in the literature about low levels of awareness about advocacy, importantly among older people themselves (Scourfield, 2007). Margiotta et al. (2003) convened three focus groups to explore what constitutes good information, advice and advocacy. When asked to describe what they thought was good advocacy practice, no one in any of the groups had anything to say due to their lack of knowledge of such services. Margiotta et al. (2003, p. 32) conclude that there is a need for better promotion of and publicity for such services:

*Access starts with the existence of a project in an area but people need to know about it, who and what is it for, how to reach it and what to expect from the service.*

In my experience, Advocare has shared the issue of a lack of awareness of its existence on the part of its client group. Margiotta et al. (2003, p. 15) makes the following suggestions about ways to increase awareness of an advocacy agency and to ensure the advocacy is effective and grounded in the needs of older people:

### **Information**

- Develop audio (e.g. cds) information for the visually impaired or those who lack literacy skills. Need to be aware that the production of leaflets in languages other than English may be cosmetic, as they are useless for people who cannot read.
- Wider more appropriate distribution of written information in places where older people live their lives day to day
- Information on websites and in all other forms must be updated regularly
- Could establish a 'reading group' of older people to review and revise information (as took place in Kensington and Chelsea (Ellis, 1999, in Margiotta et al., 2003, p. 15)

### **Advocacy**

- Older people should be provided with information about local advocacy services – their availability and ease of access.
- The older vulnerable person must be central in the advocacy process
- Advocacy must be individually led by the person in need

- Older people should be involved at all levels, whether in planning, organising, or acting as volunteer advocates
- Volunteer citizen advocates should be drawn from the many diverse groups and cultures within a community
- Health and social care practitioners should receive training about advocacy and the role of volunteer advocates
- National standards and codes of practice should be established. These would include guidelines for recruitment, training and supervision of volunteers.
- Advocare may also like to consider changing its name to something more reflective of the service it provides, as the word 'Advocare' does not easily convey this.

### **Self-advocacy**

Advocare could go further in supporting client self-advocacy by developing a self-advocacy training workshop for clients, potential clients and carers, in order to further develop their capacity to advocate on their own behalf (with reference to Fendorak & Griffin, 1986). Such training programs in other areas have provided training and technical assistance on self-advocacy, self-determination, and leadership to self-advocates (Pennell, 2001). Advocare could also look into encouraging self-advocacy through an Older People's Forum online such as that provided by the Sefton Pensioners Advocacy Centre in Manchester, whose forum hosts 1,250 people (Kitchen, 2010).

### **Citizen advocacy**

Advocare may like to expand its services to include volunteer (citizen) advocates supported by a paid generalist advocate and volunteer coordinator, as with Sefton Pensioners Advocacy Centre in Manchester (Kitchen, 2010).

### **Targeted advocacy programs**

Advocare might like to explore developing pro-active specialist advocacy programs such as the Dementia Advocacy Service by Advocacy Tasmania, or the Guardianship Advocacy Service by QADA.

### **Advocacy training**

Advocare could work with institutions of higher learning at TAFE or University level to develop an Advocacy training course or qualification for professional advocates or people who provide advocacy for others in the course of their work in the community services.

### **Evaluation**

Several different evaluation models have been discussed in this paper. Advocare may wish to consider whether their current methods of evaluation are adequate for their purposes and whether they require modification based on one or more of the alternatives mentioned.

## **Advocacy Alliance**

It has been suggested that advocacy organisations need to develop strategic links and networks with each other and other relevant movements for social change (Parsons, 1994). Parsons (1994) suggests that flexibility and adaptability of advocacy networks and structures is vital. Advocare could form an alliance with other regional advocacy agencies, for example, in Manchester there is the Manchester Advocacy Collaboration established to provide a stronger and more coherent voice for advocacy across the city. Members include:

- the African Caribbean Care Group
- the Generation Project
- the Indian Senior Citizens Centre
- Link-Age
- LMCP Care Link

Advocare could also seek to develop links with other advocacy agencies (beyond NAN) on the national level. In the UK, there have been calls for the development of a national body to operate independently of statutory services in a democratic fashion representing the interests of local advocacy initiatives and promoting and developing advocacy (Wertheimer, 1993, in Margiotta et al., 2003, p. 31). Margiotta et al. (2003) has also suggested it could be responsible for developing monitoring and evaluation criteria.

## Resources

The following resources were discovered in the course of this project:

**Action for Advocacy** - Action for Advocacy (A4A) is the central point of information on independent advocacy in England and Wales. They are a leading authority on the development of effective advocacy services for vulnerable and disempowered people. Action for Advocacy (A4A) has produced a range of publications to raise awareness of, and support the development and delivery of effective advocacy.

<http://www.actionforadvocacy.org.uk/index.jsp>

### **Advocacy Consortium UK**

ACUK is a network of networks. A consortium of national organisations, regional and local support networks and individuals operating at the national level working to promote independent advocacy. ACUK aims to be informed by people that use advocacy and all types of advocacy provision, in order to share advocacy expertise, offer mutual support to members and create opportunities to promote and enhance advocacy provision across the UK -

<http://www.acuk.org.uk/>

**Advocacy Resources Exchange (ARX)** is a UK organisation supporting the provision of Independent Advocacy - <http://www.advocacyresource.org.uk/>

**Joseph Rowntree Foundation** - The JRF is an endowed foundation funding a UK-wide research and development programme whose purpose is to inspire social change. Their website hosts many articles about research concerning older people's advocacy -

<http://www.jrf.org.uk/search/site/advocacy%20older%20people>

**National Advocacy & Training Network (NATN)** is a human rights organization comprised of an international network of survivors, volunteers, advocates, and professionals working collaboratively to end domestic abuse, sexual assault, and substance abuse. NATN offers specialized presentations, training, and in-service consultation to any community organization or group interested in learning about domestic violence, sexual assault and addiction. Additionally, NATN will help to develop effective intervention strategies and establish both short and long term training plans for agencies and institutions. - <http://www.natn-az.com/home>

**Planet Advocacy** - Planet Advocacy is A4A's quarterly magazine. It is a generic advocacy publication and targeted at anyone involved in the delivery or development of independent advocacy. Back issues of Planet Advocacy –

<http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=710&articletype=22>

**The Older Person's Advocacy Alliance** - a national UK membership based organisation supporting, promoting and developing the provision of independent advocacy services for older people. Information and resources available on their website - <http://www.opaal.org.uk>

### **Advocacy Handbooks**

Developed by Cambridgeshire County Council Social Service Department (2002) for service users and for existing and planned advocacy groups.

<http://www.cambridgeshire.gov.uk/NR/rdonlyres/319F70A9-C8D0-4AEB-81B1-D747E8959EC5/0/Advocacy.pdf>

Developed by Spice Consulting (1999) *The kit: a guide to the advocacy we choose to do* for the Department of Health and Family Services

[http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/\\$File/kit.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2CC3845B576CC54ECA2572F9000EBA99/$File/kit.pdf)

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