



# **Discussion paper on Individual Advocacy and Caring Families**

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## Executive Summary

Carers Victoria Strategic Directions 2008-2012 states that our core business includes advocacy and representation. Carers Victoria's focus is primarily on systemic advocacy on behalf of caring families and on encouraging and supporting family carers with self advocacy.

This discussion paper outlines the range of issues related to the provision of individual advocacy support for caring families, addressing the following issues:

- What is the need for individual advocacy?
- What advocacy is already available for caring families?
- What advocacy models does Carers Victoria need to consider in relation to the:
  - Current and future service system environment
  - Strategic position of our organisation?

The range of issues related to individual advocacy with a family focus includes:

- Defining advocacy types
- The limitations of self advocacy
- Interdependence of needs within caring families
- Lack of acknowledgement by service providers of the advocacy role of families
- Differences of opinion on best interests and conflicts of interest

The current provision of individual advocacy across sectors has been mapped and informs the following ratings of access by caring families:

Service system	Level of access	Rationale	Comment
Aged care	Fair	Caring families have reasonable access to ERA casework advocacy	Level of unmet need is unknown
Disability	Poor	Priority to needs of person with disability	Sector is under funded and highly fragmented
Health	Poor	No funded advocacy services	Office of Health Services Commissioner can assist with consumer complaints
Mental health	Fair	Dedicated carer advocate at ARAFEMI	Only one advocate position state-wide

A proposal to develop a model of individual advocacy for caring families is outlined along with a range of questions and issues for further consideration about the costs, benefits challenges and risks of the course of action.

## Introduction

The aim of this discussion paper is to outline the range of issues related to the provision of individual advocacy support for caring families. In a range of consultations conducted by Carers Victoria and others, many family carers have expressed a need for individual advocacy support, including a wish for casework advocacy services. This paper addresses the following issues:

- What is the need for individual advocacy?
- What advocacy is already available for caring families?
- What advocacy models does Carers Victoria need to consider in relation to the:
  - Current and future service system environment
  - Strategic position of our organisation?

## Definitions

### What is advocacy?

There are diverse views and approaches to advocacy, and considerable debate as to its definition. One of the best known and widely accepted definitions in the disability advocacy sector is that of Dr Wolf Wolfensberger:

*"...Advocacy is functioning (speaking, acting, writing) with minimum conflict of interest on behalf of the sincerely perceived interests of a person or group, in order to promote, protect or defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous, and/or which is actually, or very likely to be, costly to the advocate."* (ACT Disability, Aged and Carer Advocacy Service, 2010)

Another commonly accepted definition is *"... the process of standing alongside an individual who is disadvantaged and speaking out on their behalf in a way that represents the best interests of that person."* (Department of Health and Ageing)

FaHCSIA defines advocacy for people with disability as *"...speaking, acting or writing with minimal conflict of interest on behalf of the interests of a person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:*

- ♦ *Being on their side and no one else's*
- ♦ *Being primarily concerned with their fundamental needs*
- ♦ *Remaining loyal and accountable to them in a way which is emphatic and vigorous"*

Other definitions emphasise:

- ♦ Standing up for a person or group
- ♦ Acting in a person's best interests even if that does not coincide with one's own beliefs, opinions or recommendations
- ♦ Absence of, or minimal conflict of interest
- ♦ Helping someone understand their choices and what the impact of those choices may be
- ♦ Speaking out in support of and representing the needs and interests of a vulnerable or disadvantaged group
- ♦ Defending human rights

Advocacy can be undertaken on an informal or formal basis. For example, a person may informally self advocate about a matter or their family, carers and friends may informally advocate on the person's behalf. Alternatively, professional advocates may formally undertake advocacy on behalf of a person, family or group or a distinct population (e.g. people from culturally and linguistically diverse communities).

### **Types of advocacy**

There are three main forms of advocacy:

#### **Individual advocacy**

Individual advocacy involves supporting and promoting the rights and interests of individuals, assisting them to achieve or maintain their rights and empowering and representing their needs.

#### **Systemic advocacy**

Systemic advocacy seeks to influence positive long term changes to attitudes, systems, policies and procedures. It aims to remove barriers, address discrimination and to ensure the collective rights and interests of the represented group(s) are upheld. Systemic advocacy also seeks to influence changes to laws, government policies and the social and political structures that sustain injustice and inequality.

Currently this is the main type of advocacy that Carers Victoria aims to undertake. Carers Victoria also seeks to develop the knowledge, skills and confidence of family carers in undertaking self advocacy.

## **Self advocacy**

Self advocacy is a process in which an individual or a group of people speak or act on their behalf in pursuit of their own needs and interests and may be accompanied by training, resource kits/manuals and peer support e.g. a group of family carers who lobby for improved access to respite care services in their region.

## **Other forms of advocacy**

### **Citizen advocacy**

Citizen advocacy seeks to promote, protect and defend the rights and interests of people who have an intellectual disability by matching them with a volunteer. A citizen advocate acts on behalf of the person (or protégé) as both a friend e.g. new experiences and opportunities and an advocate e.g. speaking up and protecting the person from abuse. Wolf Wolfensberger developed the model of Citizen Advocacy through his work with parents of children with a disability who were concerned that there would be no-one to act as their child's advocate after their death. There are a small number of citizen advocacy agencies in Victoria (refer Appendix 1) however Citizen Advocacy Western is no longer in operation.

### **Peer advocacy**

Peer advocacy usually involves voluntary one-on-one support by a service user, past or present, to help another to express and fulfil their wishes e.g. a parent of a child with a disability attends a student support group meeting to provide support to another parent

### **Family advocacy**

Family advocacy is concerned with advocating on issues that affect a person with a disability and their family. The focus is usually on the needs of the person with a disability, not the parents or family e.g. training and support for parents to be more effective advocates for their sons and daughters with disabilities.

### **Legal advocacy**

Legal advocacy seeks to defend the rights and interests of individuals or groups of people through the Australian legal system e.g. representing a person with disability in a tribunal such as the Guardianship List of VCAT. Legal advocacy is undertaken by a lawyer or an individual with appropriate legal knowledge. A case study on the Villamanta Disability Rights Legal Service is on p.21.

### **What is not advocacy?**

Advocacy is always on the side of the disadvantaged party.

Advocacy is not mediation or conciliation, but can lead to one or both. Mediation involves a neutral third party who assists the parties to a dispute to:

- Identify the disputed issues
- Develop options
- Consider alternatives
- Aim to reach agreement

A mediator does not advise on or determine the content or outcome of the dispute, but does provide advice on the process. Conciliation is similar, but a conciliator:

- is an expert or someone with specialist knowledge
- may give expert advice or information
- may make suggestions about possible resolution or agreements

In practice, many advocacy situations are complex and conflicts can have a long history prior to the engagement of an advocate. It will therefore often be necessary for an advocate to engage “the other side” in a solution and to work constructively towards it. Mediation and negotiation skills will often assist an advocate to protect the rights and act in the best interests of a client.

Advocacy is not complaints handling. Good complaints handling systems recognise the need to be fair to the complainant, the agency and/or the person against whom the complaint is made. The role of an advocate will often be to support a client to see through a complaint and ensure that the agency treats the client with respect and courtesy, that the rules of natural justice are applied and that the client is given the opportunity to respond to any issues raised by the agency.

## **Family carers and individual advocacy**

### **Why is individual advocacy important for family carers?**

People with care and support needs are some of the most vulnerable people in the community. They frequently experience disadvantage and discrimination in access to services. Families commonly advocate for their family members with care and support needs, and family carers can also experience disadvantage and discrimination due to their caring role. Understanding what your rights are, navigating complex systems and negotiating legal and financial issues are challenging for consumers in any situation but

can be especially so for caring families. The separate development of the disability and mental health rights movements and the carer movement has resulted in funded individual advocacy services for people with a disability or mental illness, whilst funding for individual advocacy for family carers is so limited as to be non-existent. Family carer needs have become construed in government policy as primarily relating to emotional support, respite and education and training rather than advocacy.

### **What are the costs of self advocacy for family carers?**

Many family carers have persistently spoken out and advocated for their vulnerable family members. These advocacy efforts can and do last many years, sometimes with little or no support. They can result in significant isolation. Family carer advocates may become isolated from their communities by the very nature of their efforts, particularly where the issue is controversial or perceived as detrimental to the wider system or environment in which the issue occurs. For example, a parent's efforts to seek enrolment of a child with disability in a regular school in a local community may stir enmities, and test established friendships, the effects of which can persist over time.

Individuals often want to be connected to others doing advocacy; to share effort, seek support, or to develop a collective response. However it can be difficult for caring families to find out about and to link with peer support or advocacy groups for information, resources and contacts.

Carers consulted by ARAFEMI (2007) identified that the impact of caring, dealing with the symptoms of mental illness *and* trying to access services could be overwhelming and exhausting, even when they had the skills to be effective advocates.

### **What are the benefits of individual advocacy for family carers?**

Individual advocacy most importantly provides someone who is "on your side" and who can assist you to have your rights, needs and concerns met. Access to individual advocacy would support family carers when they:

- lack the confidence, skills and knowledge to self advocate
- have had limited success with self advocacy
- have exhausted self advocacy
- are experiencing the uncertainty of a major life transition

Individual advocacy may also be needed with complex issues that lack clearly defined boundaries e.g. a long term grievance with a service provider over the quality of care provided to a family member. A less tangible benefit to individual families is that individual advocacy issues can inform systemic advocacy on behalf of other caring families.

## **Issues in individual and family advocacy**

### **Families, caring and interdependence**

It is important to acknowledge that self advocacy by caring families is usually about the interconnected needs of the person with care and support needs and their family members. Supports required for family carers can be congruent with the supports required for the person with care and support needs. Whilst acknowledging that family carers will have their own needs unrelated to the needs of their family member, individual advocacy for a family carer will often necessarily involve advocacy for the rights and needs of the person(s) they provide care and support for.

ARAFEMI (2011) found that many of the issues that family carers requested individual advocacy for related to accessing public mental health services and accommodation services for their family member with mental illness. From our knowledge of other families and service systems, this is very likely to be the case for family carers in all care situations.

Individual advocacy for caring families would be expected to focus on both the needs of the family as a whole and on the needs of the individuals within that family. Individual advocacy does not replace self advocacy as advocates can often provide both advice and support on advocacy strategies when needed as well as provide voice to the concerns and issues experienced by caring families. An advocate can also provide specific advice in relation to individual rights.

### **Lack of acknowledgement of the role of families of adults in advocacy**

Families of people with care and support needs regularly find themselves having to deal with professionals, bureaucrats and others in roles of authority. While the authority of parents making decisions on behalf of their children is well recognised, a focus on individual rights and autonomy has resulted in poor practice in relation to family carers of adults with decision making disabilities. Partnerships between adults with a disability, their families and service providers are rarely strongly established and are frequently

characterised by tensions over difference of opinion and ideology. These experiences can leave people feeling powerless or overwhelmed. There is often a lack of recognition of the ‘natural authority’ of families (Kendrick 1996) and service providers can be too ready to resort to legal formalities even when they may not be required.

Families generally make good advocates because they:

- Have greater responsibility for the wellbeing of their family members
- Know their family member best from long term observation, insight and personal relationship
- Care about or love their family member more than others
- Are attributed decision makers especially when the person has impaired capacity
- Have a stake in outcomes because they have to live with the long term consequences of service failure
- Bear witness to the performance of services
- Bring a wide range of talents, knowledge and experience
- Are there for the long haul and can see the bigger picture
- Are relatively free of vested interest

Kendrick advocated for families of adults with an intellectual disability to re-claim their authority when it comes to deciding what will happen to their family member and to strengthen their resolve in advocacy. This is not always within the capacity and skills of all caring families. Families may also seek to engage an individual advocate in order to press service providers to recognise their natural authority.

### **Best interests**

Individual advocacy generally supports a person to achieve their preferred outcomes. This is different to best interest advocacy which focuses on solutions that a client may not wish for but that are deemed to be in their best interests.

The issue of determining a person’s best interests can be a vexed one when a person has a decision making disability and lacks capacity to give instructions to an advocate. Families are usually well placed in this regard (Kendrick 1996), but will often experience disagreement with service providers about what constitutes “best interests” especially as

best interest advocacy may result in an outcome that the person with a disability does not always agree with e.g. decisions about where to live.

Best interest advocacy also has an uncomfortable fit as it is usually not possible to set aside one's own beliefs and values in steering a person away from a course of action that is likely to have a detrimental physical, material or psychological effect.

Currently the Victorian Law Reform Commission is considering changes to the Guardianship Act that would focus on promoting a person's personal and social wellbeing rather than their best interests and on appointing supporters and co-decision makers for people with some capacity in addition to appointing substitute decision makers.

### **Conflicts of interest**

Conflicts of interest may arise when an advocate in a position of trust (informal or formal) has competing professional or personal interests with the person for whom they are advocating. A conflict of interest impinges on an advocate's ability to perform his or her duties. Conflict of interest may also arise between the needs and wishes of a person with care and support needs and their family carer who may or may not be acting as an advocate. Once again, an individual rights ideology does not acknowledge the role of family carers of people with decision making disabilities. Good practice in relation to addressing and resolving perceived conflicts of interest is rare and is more often framed as an adversarial approach with the interests of one party pitted against the interests of the other.

Most disability advocacy agencies that participated in research into the models of advocacy funded under the National Disability Advocacy Program (NDAP) were of the view that separate involvement of carer/parent advocacy may be needed in situations of conflicting rights or wishes. There was no data presented in the report on how common this situation is or evidence of any alternative approaches to conflict resolution such as mediation or conciliation. The widespread view was that family advocacy is an important model for parents of young children with a disability and may also be required where adults with a disability have close family links and/or cultural ties. There was no specific mention of the role of family advocacy for adults with decision making disability and few practice models of working in partnership with families (FAHCSIA 2009).

A strongly held view within the disability advocacy sector is while families may have substantial needs for support and resources, the rights and interests of the person with a disability are paramount and that family advocacy is about supporting family members to advocate for those rights (FAHCSIA, 2009). A literature review conducted on behalf of FaHCSIA suggested that the literature supports the provision of advocacy assistance for families and carers of people with a disability but does not identify which literature and the final report failed to make any recommendations about such a service.

In contrast, the experience of the ARAFEMI Victorian Carer Advocate Project found that consumers and carers are often aligned with agreed advocacy needs and that flexibility to work with both the carer and the consumer, or consumer bodies is essential to the advocate's role (ARAFEMI, 2011).

In practice, the belief by many disability advocacy agencies that the person with care and support needs and their family members will necessarily have conflicts of interest can be a significant hindrance to access by family carers.

### **Mapping individual advocacy across sectors:**

There is currently a fragmented array of funded individual advocacy services, with unevenly distributed resources. Some of these target the characteristics of the person needing advocacy in a range of situations such as:

- older people
- people with a disability
- people with mental illness

Some individual advocacy is targeted towards consumers of service systems such as:

- people using aged care services
- people using mental health services

Much individual advocacy is concerned with protecting the rights and interests of people using the system that is funded to provide services to them, e.g. advocacy for people with mental illness as consumers of mental health services rather than as consumers in relation to access to housing, employment etc.

## **Aged Care individual advocacy**

### **The National Aged Care Advocacy Program (NACAP)**

The National Aged Care Advocacy Program is a national program funded under the Aged Care Act 1997. The NACAP aims to promote the rights of people receiving Commonwealth Government funded aged care services including residential aged care services and community aged care (CACPs and EACH). Under the NACAP, the Department of Health and Ageing funds to community organisations to deliver aged care advocacy services in each State and Territory. However given there are over 200,000 Australians living in residential aged care and many more receiving community based aged care services, the NACAP is under resourced and not well promoted.

### **Elder Rights Advocacy (ERA, formerly Residential Care Rights Inc)**

ERA is funded under the National Aged Care Advocacy Program (NACAP) to provide advocacy services for people receiving Commonwealth funded aged care services across Victoria. Originally established by the Older Person's Action Centre in 1990, Residential Care Rights became a separately incorporated body in 2002 and commenced operating as Elder Rights Advocacy in 2007. ERA also assists carers and family members who represent the interests of the older person, as well as people who have been assessed as eligible for a Commonwealth funded aged care service. ERA provides a model of advocacy that focuses on helping older people and their representatives to understand and exercise their rights and to have those rights respected in the delivery of their care services. However individual advocacy is focused on the rights of the older person, for example to receive visitors of their choice rather than the rights of the family carer to maintain their relationship with their relative. Family carer complaints must generally relate to the care and rights of the older person rather than the treatment of the family carer by facility staff or management. ERA employs advocates with legal, social/welfare work and mediation qualifications. Services include:

- Casework advocacy
- Information provision
- Education and training
- Policy and systemic advocacy

ERA receives only approximately \$500,000 per annum in funding from Department of Health and Ageing. ERA works closely with the Aged Care Complaints Scheme as they are frequently asked to become involved in part of a complaint and commonly make referrals to Scheme. ERA also works with Seniors Rights Victoria (SRV) around issues of elder abuse.

### **CASE STUDY Seniors Rights Victoria (SRV)**

SRV is funded by the Victorian government under the Elder Abuse Prevention Strategy (EAPS) and operates under the auspices by Council on the Ageing (COTA) Victoria. SRV was established in 2008 to help prevent elder abuse and safeguard the rights, dignity and independence of older Victorians. SRV has offices in central Melbourne, the outer eastern suburbs and Bendigo. Services include:

- Legal advice
- Education and training
- Information and advice
- Referral
- Advocacy

Elder abuse is defined as mistreatment of an older person that is committed by someone with whom the older person has a relationship of trust such as a partner, family member, friend or carer. Elder abuse may be physical, social, financial, psychological or sexual and can include mistreatment and neglect. SRV will take inquiries from concerned family members or friends, but require a request for individual casework or legal advocacy to be made by the affected older person. Abuse of older people by service providers or paid staff or of older people who lack capacity to give legal instruction will be referred to the appropriate body such as the Aged Care Complaints Scheme the Office of the Public advocate (OPA).

### **Access by caring families to aged care advocacy**

Family carers do make use of the casework advocacy services provided by ERA as many complaints are initiated by family members of aged care facility residents. In 2010-2011,

from a total of 422 advocacy cases, 305 calls (72%) were from family or friend carers and 117 were from people receiving aged care services. In relation to Community Aged Care Packages (CACPs) both recipients and carers contact ERA. With Extended Aged Care at Home (EACH) package issues it's most often a family carer who contacts ERA.

*“Issues involving family members and family conflict with staff in aged care also take extended time. The current response of the industry to move (quite quickly in some instances), to restricting visits by relatives presents a concern, and impacts on the resident's right to receive visitors of their choice. Some of these issues could be addressed with enhanced staff training and complaints management within the facility, which some managers have made use of to good effect. Good communication with family members about care and treatment for people with dementia is also a vital part of avoiding conflict.” (ERA, 2010)*

## **Disability individual advocacy**

### **National Disability Advocacy Program**

The National Disability Advocacy Program (NDAP) assists people with disability to overcome barriers such as physical access, discriminatory attitudes, abuse and neglect, that impact on their daily life and their ability to participate in the community. FAHCSIA funds 62 Disability advocacy agencies across Australia to support people who are eligible for services under the Commonwealth Disability Services Act 1986.

NDAP aims to:

- Provide appropriate and timely advocacy to people with disability that addresses instances of abuse, discrimination and neglect
- Inform people with disability about their rights and responsibilities, and support them where possible in making informed decisions about issues that impact on their lives
- Contribute to raising community awareness of disability issues
- Contribute to government policy, service and program development

NDAP funds 19 agencies in Victoria (see Appendix 1). These are diverse, but are often very small organisations, even those that are state-wide. Some are regionally based, some target people with one type of disability, others support people with all types of disability. Services may be specialised to one type of advocacy only e.g. citizen advocacy

or legal advocacy while others provide a range of support for self advocacy, individual advocacy, and systemic advocacy. A 1997 review of NDAP noted a number of issues had been raised in respect of advocacy services including:

*“families concerned that some advocacy services were creating barriers between the person with the disability and their family, with the family excluded if they did not share the advocate’s philosophy”* (FaHCSIA, 2009)

The 2009 report on the NDAP commissioned by FaHCSIA found:

- A lack of resources in the advocacy sector
- A lack of awareness of advocacy
- Difficulty recruiting and retaining suitable staff
- Service gaps in regional and rural areas

Like the NACAP, the NDAP is under-resourced and only some people in need of advocacy are able to access funded services.

### **Victorian Disability Advocacy Network (VDAN) and Disability Advocacy Resource Unit (DARU)**

VDAN is a coalition of independent community based organisations working as a network to advocate for and with people with disabilities. VDAN aims to maintain an effective coalition through networking and education as well as promoting and defending advocacy. It has more than 30 member agencies including both State and Commonwealth funded agencies (see Appendix 2). Some larger State funded advocacy organisations such as the Victorian Advocacy League for Individuals with Disability Inc (VALID) and Association for Children with a Disability (ACD) are more active within VDAN and have a higher profile than other smaller agencies.

In 2005 the Department of Human Services (DHS) provided funding for two new advocacy services, the Disability Advocacy Resource Unit (DARU) and the Self Advocacy Resource Unit (SARU). SARU is aimed at increasing the ability of people with disabilities to better advocate for themselves while DARU is aimed at increasing the ability of people to better advocate on behalf of others.

DARU was established in February 2007 as a joint project of VCOSS and the Victorian Disability Advocacy Network (VDAN). The partnership was developed to enable DARU to play a significant role in ensuring the rights and interests of people with disabilities are respected and realised.

In 2010 DARU undertook a mapping exercise of disability advocacy in Victoria. Respondents were asked about the main difficulties they have in their advocacy work. Comments included that not much has changed over the years – the same difficulties are still being faced. Lack of resources was the most commonly identified issue. Other issues included:

- Lack of enough skilled staff/volunteers to meet individual needs
- Fragmented systems/lack of coordination between organisations and government
- Difficulty responding to the diverse needs of clients
- Lack of time

Many disability advocacy agencies are so small that their capacity to record and report on both individual and systemic advocacy issues is quite limited, as is their capacity to collaborate with other agencies in the network in spite of willingness to do so. Some disability advocacy agencies receive both Commonwealth and State funding and are therefore able to offer more advocacy services to more clients. However, this creates other issues of multiple accountability and reporting requirements.

## **CASE STUDY ADEC Individual Advocacy Program**

Individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion. Clients may come from any region of Victoria. Clients may have a physical, intellectual, psychiatric or sensory disability, be hearing or vision impaired, or may have an Acquired Brain Injury or Developmental Delay. Many have multiple disabilities.

The Individual Advocacy Program works in partnership with clients to achieve goals that meet their individual needs and to ensure equity of access and participation in the community.

Individual advocates assist by:

- ♦ Providing clients with information about disability services, resources and other community organisations
- ♦ Advising clients and their carers of their rights and encouraging them to voice and act upon the issues that concern them
- ♦ Supporting clients in their efforts to participate in decision making and to become actively involved in the life of the community and surrounding society
- ♦ Referring clients to government organisations and other organisations that provide culturally and linguistically appropriate services in the community

Eligible clients must:

- ♦ Be from a Non-English speaking background, or have at least one parent from a Non-English speaking country and;
  - The person must have a disability or;
  - The person is a carer and/or significant other. (A carer is defined as a person other than a paid carer caring for another person with a recognised disability)

ADEC individual advocates feed issues through to inform systemic advocacy.

### **CASE STUDY Villamanta Disability Rights Legal Service**

The Villamanta Disability Rights Legal Service provides legal assistance and casework for people who have a disability about related legal problems. Their main focus is on the rights of people who have an intellectual disability.

Current priority areas for casework advocacy include:

- ♦ Advancing the rights of people who have, or may be about to have, their finances managed by administrators
- ♦ Advancing the rights of people who have, or may be about to have, their decisions made by guardians
- ♦ Advancing the rights of people to have accommodation/services/quality of services, that meet their needs and that conform with the principles of the Disability Act 2006
- ♦ Access and equity in tribunals and with complaints mechanisms, including hearings of the Guardianship List of the Victorian Civil and Administrative Tribunal (VCAT), the Forensic Leave Panel and the Disability Services Commissioner.

Villamanta is able to:

- ♦ Represent people in tribunals, such as the Guardianship List of VCAT or the Forensic Leave Panel
- ♦ Write letters on behalf of people on matters to do with disability related legal issues
- ♦ Negotiate on behalf of people on disability related legal issues
- ♦ Give advice about disability related legal issues
- ♦ Support people to make complaints, e.g. to the Disability Services Commissioner

## **Access by caring families to disability advocacy**

Data about family carer access to disability advocacy is difficult to obtain as NDAP funded agencies are not required to collect this information. There is also significant uncertainty regarding the methods and accuracy of agencies' collection of data on consumer numbers (FaHCSIA, 2009). The sector is characterised by small, diverse advocacy groups offering different types of advocacy, some of which are state-wide and some of which are regionally based. The separate development of the disability rights movement and the carer movement has resulted in disability advocacy services being less accessible to family carers than to individuals with a disability. Anecdotally, families contacting disability advocacy services have said they are informed that advocacy is only available for issues directly affecting the person with a disability, not those affecting the family carer. The sector definition of family advocacy (p.8) would lead to the conclusion that a family carer who had been excluded or restricted from visiting their family member with a disability living in a community residential unit could not necessarily expect to receive support from a disability advocacy agency in the same way that a family carer approaching Elder Rights Advocacy would for example.

## **Health system individual advocacy**

### **Health Issues Centre (HIC)**

Health Issues Centre aims to improve the health outcomes for Australians, especially those who are disadvantaged. HIC works with consumers, health providers, researchers, governments and other health organisations to achieve this through:

- policy analysis and advocacy from consumer and equity perspectives
- consumer-focused research
- promoting and supporting consumer participation
- disseminating information

HIC does not offer individual advocacy, but offers support to health consumers in self advocacy.

## Patient Representatives

The Victorian government has adopted the Australian Charter of Healthcare Rights which outlines seven rights in access, safety, respect, communication, participation, privacy and consent. The rights described in the Charter apply to people seeking or receiving care from all healthcare services in Victoria. This includes people using public and private hospitals, GP clinics, medical specialists, aged care and disability services, mental health services, community health centres and allied health providers such as psychologists, dentists, naturopaths and occupational therapists. However, only public hospitals are required to have patient representatives to assist patients who are unable to resolve a problem with their treating team.

## Victorian Health Services Commissioner

The Office of the Health Services Commissioner:

- Provides a free and confidential service
- Helps people make their concerns known to health services providers
- Protects the right of access to consumer health information
- Conciliates formally or informally, between consumers and providers of services
- Assists in the resolution of complaints
- Uses information obtained and lessons learned to recommend improvements to services

There are no government funded independent individual advocacy services for the Victorian health system and patients may be referred to disability and mental health advocacy services if eligible. In response to this gap, some private patient advocacy services have been established that offer fee-for-service advocacy such as:

- Attending an appointment to assist the patient to ask the necessary questions and understand the answers so they are better informed about their health care plan
- Assisting a medical practitioner to form a better working relationship with a patient
- Arranging second opinions or specialist appointments for medical conditions
- Assisting in disputes with private health care funds
- Assisting in resolving confusing or conflicting medical opinions between treating practitioners
- Providing advice and guidance on available health care resources

### **Access by caring families to health advocacy**

Access by health service consumers and their families to individual advocacy is limited. Patient representatives are not fully independent advocates; as employees of hospitals or health networks they are not able to be completely autonomous from service provision. The Office of the Health Services Commissioner can assist health consumers and their families to approach a health provider and discuss their concerns, but is not an advocate. Only some families would be able to afford to pay a private advocate to assist them.

### **Mental health individual advocacy**

The National Disability Advocacy Program (NDAP) also funds advocacy to assist people with mental illness as this is an eligible disability type under the Commonwealth Disability Services Act 1986.

### **Victorian Mental Illness Awareness Council (VMIAC)**

In Victoria the NDAP funds VMIAC, which employs three advocates who provide coverage across Victoria. All VMIAC staff must have experienced mental health or emotional issues in their own lives. VMIAC believes that this is essential to ensure that their commitment and accountability are always unwaveringly with the consumer. Advocacy activities include individual, group and systemic advocacy.

Individual advocacy can be accessed by any person who has a mental illness or emotional problems (consumer). Issues needing the support of an advocate are usually to do with some aspect of mental health service provision (clinical or psychosocial rehabilitation services), but may include any issue confronting a consumer.

### **Consumer consultants and carer consultants**

The Victorian government funds the consumer consultants and carer consultants who are employed in public mental health services to represent the interests of consumers and carers, respectively, and advocate for their needs. Use of this strategy within a mental health service is a means to promote services that are responsive to the needs of consumers and carers. They take on a variety of roles, including:

- ♦ building relationships with individual consumers and carers and communicating their needs to health professional staff

- ♦ investigating and advocating areas for improvement to local services, policy and procedures
- ♦ participating in the selection of staff employed in the local services
- ♦ advocating consumer and carer perspectives in the evaluation of local services and
- ♦ contributing to training programs for service delivery staff

Consumer or carer consultants' capacity to undertake individual advocacy is limited by hours of employment, skill levels and the difficulties of individual advocacy within the organisation that employs the consultant. In 2004-05 only 1.8 FTE carer consultants were employed per 1000 FTE clinical staff across Victoria which was higher than the national average of 0.7 (Department of Health and Ageing 2007).

### **Mental Health Legal Centre**

The Mental Health Legal Centre receives the majority of its funding from the Victorian Department of Health and Victoria Legal Aid. The Centre does a variety of legal advocacy work, but only if the legal problem relates directly to the mental illness. They may be able to assist with:

- ♦ Complaints about the Mental Health System
- ♦ Complaints about Involuntary Detention or Community Treatment Orders (CTOs) including representation of people on CTOs at the Mental Health Review Board
- ♦ Problems with Criminal Law
- ♦ Problems with Child Protection
- ♦ Disputes in Family Law
- ♦ Human Rights and Discrimination
- ♦ Complaints about Guardians or Administrators, including representation at VCAT
- ♦ Accessing Medical and other Records
- ♦ Other legal problems that relate directly to the person's mental illness

The service is only available to Victorian consumers (or their representatives provided consumer permission has been obtained) about their own issues.

**CASE STUDY ARAFEMI** (formerly Association of Relatives and Friends of the Emotionally and Mentally Ill) **Carer Advocate Program**

ARAFEMI is both the peak support agency for carers of people with a mental illness and also provides a broad range of consumer services. The Carer Advocate Program provides a free state-wide casework advocacy service to carers across all areas of mental health and includes both the public and private system. The role is service-neutral, in that ARAFEMI is not attached to any particular public or private mental health service, and provides an objective perspective with few opportunities for conflict of interest.

It enhances existing systemic advocacy structures and compliments group, individual and systemic advocacy approaches by offering access to a service neutral carer advocate who is able to provide individualised case work services and supports to mental health carers.

*“Consumers and carers were more frequently in agreement and seeking same outcomes from the advocate than would have been imagined through the political lens of the consumer and carer movements. The use of a carer advocate complemented and supported the needs of both the consumer and the carer”* (ARAFEMI, 2011)

**Access by caring families to mental health advocacy**

Carers of people with mental illness are the only group identified that has an individual advocacy service targeted at their needs. ARAFEMI received 126 individual casework advocacy referrals in the first 18 months of operation. The main issues identified were:

- Communication difficulties with mental health service
- Lack of carer involvement in discharge planning
- Formal complaints against services
- Accessing appropriate supported accommodation for consumers
- Accessing appropriate services for consumers
- Centrelink difficulties
- Carer financial difficulties

An important feature of the service is that although ARAFEMI delivers services including outreach recovery and rehabilitation, they do not provide clinical mental health services and therefore offer what is called a service-neutral approach. The Carer Advocate position sits within a broad range of family carer supports (Helpline, support groups and carer education) and builds on multiple levels of carer involvement in the organisation.

Although there is only one carer advocate position for Victoria, and in the pilot period, the project has been limited to provision of 1:1 casework in metropolitan Melbourne with limited support to rural and regional Victoria, it is not intended that the carer advocate can provide a one stop shop or extended support. The evaluation found that placement of a service neutral carer advocate within a state-wide carer support service, best utilised resources for targeted and cost effective interventions, but future growth of this pilot demonstration service is uncertain.

### **Do caring families have adequate access to individual advocacy?**

Based on mapping of the various individual advocacy services across aged care, disability, health and mental health sectors, access by caring families can be rated only poor to fair as follows:

<b>Service system</b>	<b>Level of access</b>	<b>Rationale</b>	<b>Comment</b>
Aged care	Fair	Caring families have reasonable access to ERA casework advocacy	Level of unmet need is unknown
Disability	Poor	Priority to needs of person with disability	Sector is under funded and highly fragmented
Health	Poor	No funded advocacy services	Office of Health Services Commissioner can assist with consumer complaints
Mental health	Fair	Dedicated carer advocate at ARAFEMI	Only one advocate position state-wide

### **Government policy on funded advocacy services**

In 2009 FaHCSIA engaged consultants Jenny Pearson and Associates to research the models of advocacy funded under the National Disability Advocacy Program (NDAP). It

concluded that of the six models of advocacy funded under the NDAP, individual advocacy is the model that has the best potential to provide immediate advocacy assistance across a wide range of issues to the greatest number of Australian with a disability, but that a significant barrier to effectiveness was the lack of resources in the advocacy sector. Key recommendations included:

- Individual Advocacy should be the primary model of advocacy funded through the NDAP and that Individual Advocacy should have a flexible definition enabling the additional use of, or referral to, a range of other advocacy models as required by consumers
- In consultation with the advocacy sector, FaHCSIA should facilitate a National Systemic Advocacy Forum involving representatives of state/territory advocacy networks, national disability peak bodies and relevant government representatives to consider systemic issues, examine supporting evidence, prioritise issues and provide appropriate input to government policy agenda

The report is available on the FaHCSIA website, but there does not appear to have been any action on the recommendations other than in the area of national key performance indicators (KPIs) in line with other FaHCSIA funded community services programs.

### **Productivity Commission recommendations**

The Productivity Commission's two recent reports on inquiries into Caring for Older Australians and Disability Care and Support both made recommendations to expand funding for individual advocacy under the NACAP and the NDAP respectively. They also made recommendations that Carer Support Centres should be developed from the existing specialist carer support service programs. Although there are inconsistencies between the two reports, the report on Caring for Older Australians considered that Carer Support Centres would deliver services including:

- Education and training
- Emergency respite
- Counselling and peer support
- Carer advocacy services

The report on Disability Care and Support suggested that advocacy would be block funded separately by FaHCSIA alongside the proposed National Disability Insurance Scheme, but also that advocacy would be a role undertaken by the proposed Local Area Coordinators.

The Commission has identified that the sweeping changes recommended for both the aged care and disability support systems in Australia would result in an increased need for consumers of those services, including carers to access individual advocacy.

Commissioner Robert Fitzgerald, speaking at the Community Services and Health Industry Skills Council Conference on 19 October 2011 said adoption of the Commission's market-orientated recommendations could lead to the development of a new area of service – aged care consumer advocacy. Some older, vulnerable consumers will be unable to make a decision about the type of care they want without additional help and support.

*"It is true that for some, choice is an illusion so we must ensure that [all] consumers have choice, and [there are] supports for those who are vulnerable."* The role of the aged care advocate or intermediary would therefore *"grow in importance...as people are expected to make choices"*. (Australian Ageing Agenda 25/10/2011)

The report on Caring for Older Australians did not make any recommendations about the connection between individual advocacy and systemic advocacy that would identify gaps and system failures and promote ongoing system change and improvement whereas the report on Disability Care and Support did make some of these links (above).

### **Other issues in individual advocacy provision**

As outlined, gaps in advocacy for carers, scarcity of available individual advocacy and service boundaries on access to support limits the ability of caring families to have their needs addressed.

Gippsland Carers Association (GCA) is one group that believes that family carers do not currently have access to individual advocacy. They are critical of family advocacy models that support families to advocate for people with disabilities and that do not advocate on behalf of the needs and interests of families. They are also critical of the role of Carer Associations, who they view as receiving government funds for advocacy, but representing family carers without consulting or giving voice to their real concerns. They propose:

- Regional Family Support and Advocacy Networks as the “missing link” in support services for caring families

- That governments must fund 44 regional networks nationwide to ensure that there is a 'grass roots' support service that can be accessed by caring families, close to where they live
- Creating a level playing field with Disability Self Advocacy, Aged Residential Advocacy and Service Provider Advocacy

They have established a campaign requesting that both State and Federal politicians to support this funding as a matter of urgent priority. GCA has received correspondence from the Victorian Disability Advocacy Network (VDAN) advising that VDAN:

- does not agree with GCA's views on accommodation and support
- will not be distributing campaign materials or supporting the campaign
- offers to meet and discuss concerns and work to develop a collaborative approach

Carers Victoria remains equivocal about the model and it's costing and has advised GCA that system design for individual and systemic advocacy needs to be addressed in the context of forward planning for a National Disability Insurance Scheme. In addition the relationship between their proposed model of Regional Family Support and Advocacy Networks and other existing services is far from clear.

### **How could an individual advocacy model operate for caring families?**

An individual advocacy service could assist in meeting the needs of caring families who are struggling with the systems that they must deal with in support of their family member such as the aged care, disability, health, mental health and social security systems. Advocacy would also assist with other "systems" impacting on caring families such as the carer support, housing, transport, education and employment systems. Individual advocacy also helps to "fill in the gaps"; providing powerful case studies and key data collection to inform systemic advocacy (refer Figure 1 on p.34).

A caring family advocacy service needs to have the capacity to work with all members of a family affected by the identified issue and to work across service systems. Advocates need to be able to work with service providers on behalf of their clients, gaining acceptance as people with the skills to help providers find a satisfactory resolution to a problem that may have become identified as an interpersonal issue with an individual

carer. Advocates need to also support family carers to develop the confidence and skills so that they can better advocate for themselves.

## **CASE STUDY**

### **Association for Children with a Disability (ACD) Parent Support Service**

ACD considers that every member of families of children with a disability need and deserve support: children themselves, siblings, parents, grandparents and other extended family. Parent Support Workers provide support by listening, understanding (they are themselves parents of children with a disability) and providing information and advice.

ACD's approach is oriented to helping parents to be their own best advocates.

However, in certain situations, Parent Support Workers will attend meetings to act as an advocate for parents/carers. ACD provides tips on *How to be Your Own Best Advocate* and *Tips for Advocating on Behalf of Others* for peer advocates

## **Principles for effective advocacy**

Advocacy is about securing the best possible outcome for the client; therefore, a strong ethical emphasis regarding practice principles is essential. The following principles (Bateman 2000) provide an ethical framework for advocacy practice:

- ♦ Act in the client's best interests
- ♦ Act in accordance with the client's wishes and instructions
- ♦ Keep the client properly informed
- ♦ Carry out instructions with diligence and competence
- ♦ Act impartially and offer frank, independent advice
- ♦ Maintain client confidentiality

Taking these basic principles, with their assumption of an individual "client" in conjunction with family centred practice principles, a set of principles and practice for individual advocacy work with caring families would need to be established.

## Possible issues that may be dealt with through individual advocacy

Based on current complex issues that are put through for advice to the policy team from the Carer Advisory Line, possible issues include:

- ♦ Financial/legal e.g. Centrelink, Guardianship and Administration, Powers of Attorney, Succession planning, Wills, Immigration/Carer Visa etc.
- ♦ Service gaps/complaints e.g. aged care, disability, mental health, education, health services, HACC, community packaged care, disability individual support packages, respite services, brokerage, regional inequity, ineligibility, waiting lists
- ♦ Housing, supported accommodation and residential care service issues
- ♦ Employment issues for family carers

It is likely that individual advocacy cases would be a combination of “bounded” and “unbounded” problems (Watson and Watson, cited in Bateman, 2000).

Features of bounded problems:

- Limited timeframe
- Clear priorities
- Limited applications
- Discrete matters
- Limited number of people
- Problem and solution are readily identifiable

Examples include: refusal of Carer Allowance, exclusion of child with a disability from school, a decision by a service provider to reduce the hours of respite.

Features of unbounded problems:

- Appear to have no ready solution
- Uncertain timeframe and resource requirements
- Hard to disentangle from their context
- Involve more people
- Many unknowns

Examples include: disagreement about a decision on medical treatment, a complaint about a staff member's conduct, most inter-personal and family disputes

Bounded problems are characterised by rules, regulations and procedures and will usually have a clear structure for resolving disputes or different interpretations of guidelines. The relevant rules and regulations will then form the basis for any action by an advocate.

However, work with caring families is often characterised by unbounded problems based on interpersonal issues and lack a clear structure or process to follow. An advocate then needs to employ negotiation and mediation skills to be able to "steer a path" through to a satisfactory outcome for the client, which is often very resource intensive.

## **Carers Victoria advocacy**

### **Our Vision**

Caring: a shared community responsibility

### **Our Mission**

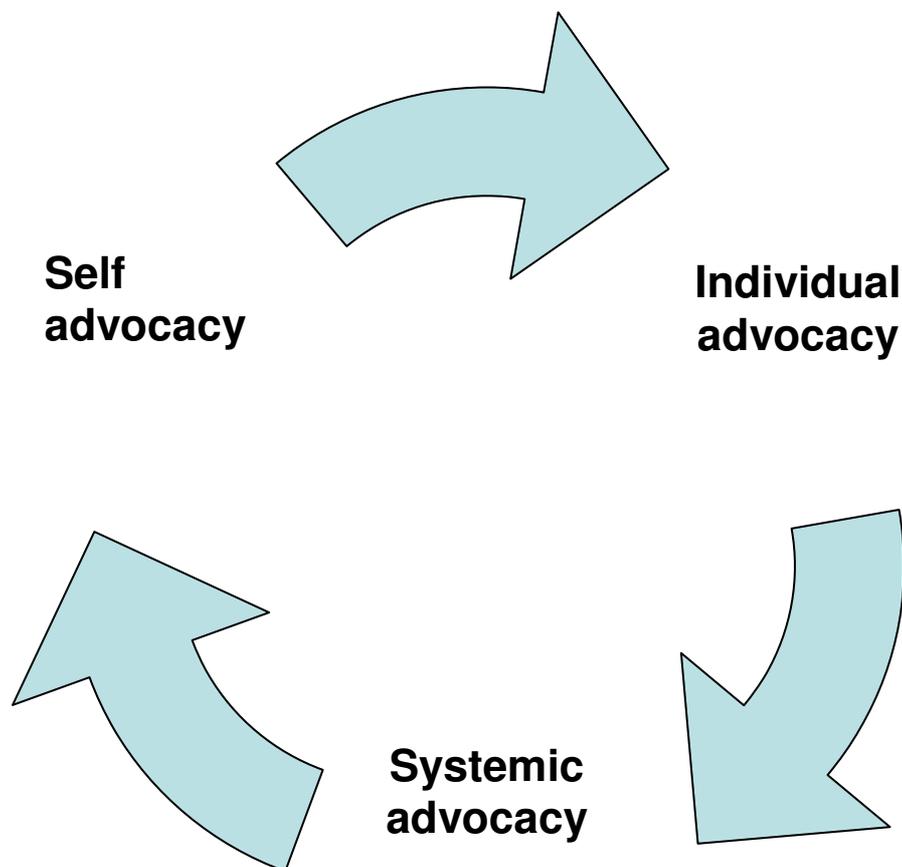
Leading change in services, systems and supports for caring families

Carers Victoria Strategic Directions 2008-2012 states that our core business includes advocacy and representation. Carers Victoria's focus is primarily on systemic advocacy on behalf of caring families and on encouraging and supporting family carers with self advocacy. Some limited one to one advocacy has occurred via the advisory line with support from the policy team and the CEO. These are usually instances where a family carer is considered especially disadvantaged and where committing resources to individual advocacy holds some prospect of influencing systemic change. In the past Carers Victoria's work in engaging family carers in self advocacy has included:

- Carers Speak Out report on consultations with carers in Southern Metropolitan and Grampians regions
- Action Pack self advocacy kit for carers
- Speak Up and Speak Out self advocacy workshops
- Regional Carer Representation Project and Regional Advocacy Forums
- Election platforms and the Every Australian Counts NDIS campaign

## Linkages between self, individual and systemic advocacy

Figure 1: Individual advocacy as a key part of the advocacy picture



Individual advocacy would support caring families who have complex issues that are unable to be resolved via self advocacy. Data and case studies from individual advocacy would inform our systemic advocacy work which in turn provides resources to assist individuals and groups of carers to advocate for themselves.

### What could Carers Victoria offer in the area of individual advocacy?

#### Our strengths

Carers Victoria is well placed in many ways to fill a support gap by offering an individual advocacy service to caring families. Carers Victoria has established:

- Principles for family centred practice
- Next steps for reducing the divide between disability and carer policy

- A skilled and knowledgeable Carer Engagement and Representation Stream
- A continuously staffed entry point via the Carer Advisory Line with connection to the policy team for complex issues
- Capacity to travel for state-wide coverage
- Sector engagement with the Victorian Carer Services Network (VCSN)
- Strategic analysis of the current and future service system environment

### Our challenges

Recalling the Wolfensberger definition of advocacy “*which is actually, or very likely to be, costly to the advocate*”, there are risks to the organisation and to staff taking on an advocacy role that would need to be considered and managed. Carers Victoria would need to address capabilities and resources in the following areas:

- **Funding:** Could Carers Victoria self fund this project or would we need to seek additional funding? Where is the fit with strategic planning at the national network level?
- **Neutrality:** As a current provider of carer support services, could Carers Victoria advocate effectively for clients who have issues or complaints about Carer Counselling, Respite Connections or other Commonwealth Respite and Carelink Centres?
- **Sector engagement:** How to identify the key stakeholders and seek their support e.g. would VCSN members support a service that may advocate for clients unhappy with carer support services?
- **Service overlap and interagency referral protocols:** Would there be a need for all advocacy requests about the school system be initially referred to ACD, requests about residential aged care to ERA and requests about the mental health system to ARAFEMI?
- **Connections to Carers Victoria systemic advocacy:** How would individual advocacy effectively inform our systemic advocacy and how would it guide prioritisation of issues?
- **Staffing:** Would advocates be part of an existing team or form a new team within the Carer Engagement and Representation Stream? What is the interface with

education and training workshops on self advocacy? What is the interface with the broader carer engagement program?

- **Service limitations and connections to other forms of advocacy:** What mechanism would be needed to support caring families to access funded legal advocacy or pro bono legal support?
- **Demand management:** What intake procedures and prioritisation strategies would be required and who would undertake these? What mechanisms would be required for clients who do not receive priority?
- **Staff support and supervision:** What level of access to problem solving, de-briefing, and external supervision would be required?
- **Negative consequences of advocacy:** How to deal with complaints by clients or service providers about the actions of an advocate?

## Options

Embarking on an individual advocacy project provides the following opportunities:

### Data collection:

- Formal consultation with caring families about the need for and design of an individual advocacy service e.g. survey monkey
- Establishment of an advocacy log with training and procedures for all Carers Victoria staff to input the advocacy issues they have identified into the development of systemic advocacy priorities

### Service model, design and quality:

- Further development of model of practice with a focus on the need of the whole family rather than one carer, or just one person with care and support needs
- An individualised service that allows work with one or all family members as necessary
- A considered response to families who do not act in the best interests of their family member with carer and support needs and action on exploitative or abusive relationships

**Project management:**

- Establishment of an internal project team to work through the challenges before and during the project
- Establishment of an external reference group including family carer representation to develop stakeholder engagement and acceptance

**Relationship building:**

- With the disparate carer support groups across Victoria
- With groups that are critical of Carers Victoria e.g. disability advocacy organisations, Gippsland Carers Association
- With other advocacy organisations
- With government and service providers

**Measure of demand:**

- Establishing the costs and benefits of advocacy
- Examining the feasibility of delivering a state-wide advocacy service and equity of access with central or regionally based access
- Determining the necessary training and quality standards

**Communication strategy:**

- Further promotion of next steps in reducing the divide between disability and carer policy
- Promotion of the advocacy service to both caring families and service providers as a means of resolving issues and improving communication

## Responses to opportunities and risks

In the context of significant service system change in disability support and aged care and reforms in mental health and aged care, a proactive course of action would position Carers Victoria strategically. Developing a model, instituting a pilot project and evaluating the outcomes would inform further action. Responses to the broader reform agendas would position Carers Victoria to be considered for future funding of carer advocacy services as recommended by the Productivity Commission. The strategic positioning of the National Network of Carer Associations also requires consideration.

Possible consequences of not developing and piloting a model of individual advocacy for caring families include:

- A loss of role for Carers Victoria in “specialist” carer support services to regional carer support centres
- An underdeveloped model of carer advocacy which lacks independence
- Further divide between disability rights and carer movements

## How would we know if our advocacy is effective?

Measurement of the effectiveness of an individual advocacy service could include:

- Satisfaction – how many caring families were satisfied that the service they received met their needs
- Coverage – how many caring families in each region of Victoria accessed the service
- Output – how many caring families were assisted each year
- Diversity – how many different types of caring families were assisted
- Demand - how many caring families were not able to be assisted

These measures would be complemented by qualitative measures such as case studies and individual advocacy issues that have been taken up as systemic issues. Other considerations include measures of cost effectiveness and the degree of independence from service provision.

Finally, it will be important to have a means of assessing any unanticipated negative consequences of the project for other areas of the organisation.

## Conclusion

Advocacy is complex because the issues that require advocacy are rarely straightforward. It is evident that there is a lot of scope to improve the access of caring families to individual advocacy. Carers Victoria is well placed as a state-wide body to initiate a demonstration project and develop an effective model of family focused individual advocacy. This opportunity presents a number of challenges and risks and requires considerable further analysis, planning and development to progress the proposal. Next steps could include:

- Identification of available resources including those that could be re-directed towards advocacy
- Development of a brief for a demonstration pilot and evaluation project
- Table the proposal for discussion at the strategic planning meeting in February 2012

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## APPENDIX 1: Overview of Victorian Disability Advocacy Organisations

### Commonwealth funded agencies

NDAP funded agency	Service Area	Specialisation	Services provided	Contact details
Action for More Independence & Dignity in Accommodation Inc (AMIDA)	State-wide	Better access to housing for people with a disability, particularly intellectual disability	<ul style="list-style-type: none"> <li>• Telephone advice, information, referral and support</li> <li>• Individual advocacy</li> <li>• Education about housing rights</li> </ul>	Ross House 1st Floor 247 Flinders Lane Melbourne 3000 Phone: 03 9650 2722 Fax: 03 9654 8575 Email: <a href="mailto:amida@infoxchange.net.au">amida@infoxchange.net.au</a> Web: <a href="http://www.amida.org.au/">http://www.amida.org.au/</a>
ADEC - Advocacy, Disability, Ethnicity, Community (formerly Action on Disability within Ethnic Communities Inc)	State-wide	People with a disability or their family carers who are from a non-English speaking background	<ul style="list-style-type: none"> <li>• Individual Advocacy</li> <li>• Family Advocacy</li> <li>• Self Advocacy</li> <li>• Systemic Advocacy</li> </ul>	175 Plenty Road Preston VIC 3072 Phone: 03 9480 1666 Fax: 03 9480 3444 Free call: 1800 626 078 Email: <a href="mailto:info@adec.org.au">info@adec.org.au</a> Web: <a href="http://www.adec.org.au/">http://www.adec.org.au/</a>
Association of Employees with Disability Inc (AED Legal Centre)	State-wide	Legal advocacy to people with a disability in the areas of employment, education and training	<ul style="list-style-type: none"> <li>• Negotiate workplace solutions</li> <li>• Draft complaints of discrimination or unlawful dismissal</li> <li>• Provide legal representation to people with a disability</li> <li>• Educate employees with a disability about their legal rights</li> </ul>	Suite 4, Level 5 2-26 Elizabeth Street Melbourne VIC 3000 Phone: 03 9639 4333 Fax: 03 9650 2833 Email: <a href="mailto:noni.lord@aed.org.au">noni.lord@aed.org.au</a> Web: <a href="http://www.aed.org.au/">http://www.aed.org.au/</a>
Citizen Advocacy Sunbury &	LGAs of Hume and Macedon	People with an intellectual disability	Citizen advocacy	36 Macedon Street Sunbury VIC 3429

<b>NDAP funded agency</b>	<b>Service Area</b>	<b>Specialisation</b>	<b>Services provided</b>	<b>Contact details</b>
Districts Inc	Ranges			Phone: 03 9744 7378 Fax: 03 9740 8535 Email: <a href="mailto:casunbury1@bigpond.com">casunbury1@bigpond.com</a>
Colac Otway Region Advocacy Service (CORAS)	LGAs of Colac-Otway and Surf Coast	People with intellectual disability, physical disability, psychiatric impairment	Individual and systemic advocacy	50 Rae Street Colac VIC 3250 Phone: 03 5232 1009 Fax: 03 5232 1291 Email: <a href="mailto:coras@bigpond.com">coras@bigpond.com</a>
Disability Advocacy and Information Service Inc (DAIS)	LGAs of Alpine, Benalla, Indigo, Mansfield, Towong, Wangaratta and Wodonga	People with all types of disability	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Systemic advocacy</li> <li>• Community education</li> <li>• Self advocacy training</li> <li>• Outreach</li> <li>• Regional service of Disability Rights Victoria – individual advocacy for people with physical and multiple disability</li> <li>• HACC Equity &amp; Access Program</li> </ul>	20 Stanley Street Wodonga VIC 3690 Phone: 02 6056 2420 Fax: 02 6024 6809 Email: <a href="mailto:admin@dais.org.au">admin@dais.org.au</a> Web: <a href="http://www.disability-advocacy.com.au/">http://www.disability-advocacy.com.au/</a>
Disability Justice Advocacy Inc (DJA)	Melbourne metropolitan LGAs only	People with high support needs as a result of physical or multiple disability	Individual and systemic advocacy	86-88 Herbert Street NORTHCOTE VIC 3070 Phone: 03 9481 7022 Fax: 03 9489 2988 Email: <a href="mailto:info@justadvocacy.com">info@justadvocacy.com</a> Web: <a href="http://www.justadvocacy.com/">http://www.justadvocacy.com/</a>

<b>NDAP funded agency</b>	<b>Service Area</b>	<b>Specialisation</b>	<b>Services provided</b>	<b>Contact details</b>
Disability Rights and Advocacy Service Inc (DRAS)  (service contract transferred to RIAC from 1 <sup>st</sup> July 2011)	LGAs of Greater Geelong and Queenscliff	People with all types of disability	Individual and systemic advocacy	38 Myers Street GEELONG VIC 3220 Phone: 03 5221 8033 Fax: 03 5223 2701 Email: <a href="mailto:info@dras.org.au">info@dras.org.au</a> Web: <a href="http://dras.org.au/">http://dras.org.au/</a>
Gippsland Disability Advocacy Inc	LGAs of Bass Coast, Baw Baw, East Gippsland, Latrobe, South Gippsland and Wellington	People with all types of disability	Individual, systemic and family advocacy	58 - 60 Commercial Road Morwell VIC 3840 Phone: 03 5133 9440 Fax: 03 5133 9897 email: <a href="mailto:gippsadv@bigpond.com">gippsadv@bigpond.com</a>
Grampians disAbility Advocacy Association Inc	LGAs of Ararat and Northern Grampians, Moorabool, Hepburn and Golden Plains	People with all types of disability	Individual advocacy and support to self advocates	Shop 2, 32 Tuson Street Ararat VIC 3377 Other offices in Daylesford, Geelong and Bacchus Marsh Phone: 03 5352 2722 Fax: 03 5352 2733 Email: <a href="mailto:asas@netconnect.com.au">asas@netconnect.com.au</a>
Leadership Plus Inc (formerly Action for Community Living)	State-wide	People with all types of disability plus a speciality in acquired brain injury (ABI)	Individual and systemic advocacy	86-88 Herbert Street Northcote VIC 3070 Phone: 03 9489 2999 TTY: 03 9489 1179 Fax: 03 9489 2988 Dandenong office services LGAs of Casey, Greater Dandenong and Kingston Email: <a href="mailto:acl@afcl.org.au">acl@afcl.org.au</a> Web: <a href="http://www.leadershipplus.com/">http://www.leadershipplus.com/</a>
Melbourne East Disability Advocacy (formerly Citizen Advocacy Inner East)	LGAs of Boroondara, Manningham, Monash and Whitehorse	People with an intellectual disability	Provides individual advocacy and organises volunteer advocates to be matched with people in the community with	1059 Riversdale Road Surrey Hills VIC 3127 Phone: 03 9808 8633 Fax: 03 9808 8633

NDAP funded agency	Service Area	Specialisation	Services provided	Contact details
			intellectual disabilities	Email: <a href="mailto:office@meda.org.au">office@meda.org.au</a> Web: <a href="http://www.meda.org.au">http://www.meda.org.au</a>
North East Citizen Advocacy Inc (NECA)	LGAs of Banyule, Darebin, Nillumbik and Whittlesea	People with an intellectual disability	Citizen advocacy	56 Garbonia Avenue Watsonia VIC 3087 Phone: 03 8407 3684 Fax: 03 8407 3684 Email: <a href="mailto:neca@citizenadvocacy.com.au">neca@citizenadvocacy.com.au</a> Web: <a href="http://www.citizenadvocacy.com.au/">http://www.citizenadvocacy.com.au/</a>
Regional Information and Advocacy Council Inc (RIAC)	LGAs of Buloke, Campaspe, Central Goldfields, Gannawarra, Greater Bendigo, Greater Shepparton, Loddon, Macedon Ranges, Mitchell, Moira, Mount Alexander, Murrindindi, Strathbogie and Swan Hill, Mildura. In New South Wales - Balranald and Wentworth	People with all types of disability	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Systemic advocacy</li> <li>• Self advocacy</li> <li>• Family advocacy</li> </ul>	190 Benalla Road Shepparton VIC 3630 Other offices in Bendigo and Mildura Phone: 03 5822 1944 Freecall: 1800 221 944 Fax: 03 5831 1610 Email: <a href="mailto:enquiry@riac.org.au">enquiry@riac.org.au</a> Web: <a href="http://www.riac.org.au/">http://www.riac.org.au/</a>
Southern Disability Advocacy Inc	LGAs of Bayside, Glen Eira, Kingston, Port Phillip and Stonnington	People with intellectual or psychiatric disability	Individual, systemic and citizen advocacy	Suite 5, 115 Bluff Road BLACK ROCK VIC 3193 Phone: 03 9533 5977 Fax: 03 9533 5988 Email: <a href="mailto:info@southernda.org.au">info@southernda.org.au</a> Web: <a href="http://www.southernda.org.au">http://www.southernda.org.au</a>
Southwest Advocacy Association Inc	LGAs of Corangamite, Glenelg, Moyne, Southern Grampians and Warrnambool	People with all types of disabilities	Individual and systemic advocacy	31 Princess Street Warrnambool VIC 3280 Phone: 03 5561 4584 Fax: 03 5561 4371 Email:

NDAP funded agency	Service Area	Specialisation	Services provided	Contact details
				<a href="mailto:swadvocacy@bigpond.com">swadvocacy@bigpond.com</a> Web: <a href="http://www.southwestadvocacy.org.au/swaa/">http://www.southwestadvocacy.org.au/swaa/</a>
Victorian Mental Illness Awareness Council (VMIAC)	State-wide (when combined with Victorian government funding)	People with psychiatric impairment	<ul style="list-style-type: none"> <li>• Advocacy and Representation</li> <li>• Information and Peer Support</li> <li>• Research and Evaluation</li> <li>• Education and Training</li> </ul>	Building 1/22 Aintree Street Brunswick VIC 3056 Phone: 03 9380 3900 Fax: 03 9388 1445 Email: <a href="mailto:director@vmiac.org.au">director@vmiac.org.au</a> Web: <a href="http://www.vmiac.org.au/">http://www.vmiac.org.au/</a>
Villamanta Disability Rights Legal Service Inc	State-wide	People with intellectual disability and accepts all other disabilities	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Legal advocacy</li> </ul>	44 Bellerine Street GEELONG VIC 3220 Phone: 03 5229 2925 or 1800 014 111 (Legal matters only) Fax: 03 5229 3354 Email: <a href="mailto:legal@villamanta.org.au">legal@villamanta.org.au</a> Web: <a href="http://www.villamanta.org.au/">http://www.villamanta.org.au/</a>
Westernport Speaking Out Inc	LGAs of Bass Coast, Cardinia, Casey, Frankston, Greater Dandenong, Kingston and Mornington Peninsula	People with an intellectual disability	Self advocacy	Unit 6/44 Beach Street Frankston VIC 3199 Phone: 03 9770 1710 Fax: 03 9783 5282 Email: <a href="mailto:wpsso@bigpond.net.au">wpsso@bigpond.net.au</a>

## APPENDIX 2: Overview of Victorian Disability Advocacy Organisations

### Victorian funded agencies

State funded agency	Service Area	Specialisation	Services provided	Contact details
Able Australia	State-wide	People with a range of multiple disabilities including deaf-blindness	Service provider with an advocacy arm for their client group	PO Box 1213 Camberwell Victoria 3124 Phone: 1300 225 369 Email: <a href="mailto:info@ableaustralia.org.au">info@ableaustralia.org.au</a> Web: <a href="http://www.ableaustralia.org.au">http://www.ableaustralia.org.au</a>
ARBIAS	State-wide	People with alcohol related brain impairment	Family advocacy	27 Hope St Brunswick Victoria 3056 Phone: 03 8388 1222 Email: <a href="mailto:arbias@arbias.com.au">arbias@arbias.com.au</a> Web: <a href="http://www.arbias.com.au">http://www.arbias.com.au</a>
ASSERT 4 ALL (formerly Barwon disAbility Resource Council (BDRC))	LGAs of Greater Geelong, Queenscliff, Surf Coast, Moorabool and Golden Plains	People with all types of disability	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Self advocacy Training</li> </ul>	48 McKillop Street Geelong VIC Victoria 3220 Phone: 03 5221 8011 Email: <a href="mailto:info@bdrc.org.au">info@bdrc.org.au</a> Web: <a href="http://www.bdrc.org.au/">http://www.bdrc.org.au/</a>
Association for Children with a Disability	State-wide	Children with a disability and their families	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Family advocacy</li> <li>• Systemic advocacy</li> </ul>	Suite 2, 98 Morang Road Hawthorn Victoria 3122 Phone: 03 9818 2000 or Freecall: 1800 654 013 Email: <a href="mailto:mail@acd.org.au">mail@acd.org.au</a> Web: <a href="http://www.acd.org.au/home/in">http://www.acd.org.au/home/in</a>

State funded agency	Service Area	Specialisation	Services provided	Contact details
				<a href="#">dex.htm</a>
Blind Citizens Australia (BCA)	State-wide	People who are blind or vision impaired	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Systemic advocacy</li> </ul>	Ross House 247-251 Flinders Lane Melbourne Victoria 3000 Phone: 03 9654 1400 Email: <a href="mailto:bca@bca.org.au">bca@bca.org.au</a> Web: <a href="http://www.bca.org.au">http://www.bca.org.au</a>
Brain Injury Matters (formerly Bear in Mind)	North and West Metropolitan region	People with an acquired brain injury (ABI)	Self advocacy	Ross House, 4th Floor 247 Flinders Lane Melbourne Victoria 3000 Phone: 03 9639 7222 Email: <a href="mailto:office@bim.org.au">office@bim.org.au</a> Web: <a href="http://www.bim.org.au">http://www.bim.org.au</a>
Communication Rights Australia	State-wide	People with little or no speech	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Group advocacy</li> <li>• Systemic advocacy</li> </ul>	Unit 4, 3 Tuck Street Moorabbin Victoria 3189 Phone: 03 9555 8552 or 03 9555 8948 Email: <a href="mailto:info@caus.com.au">info@caus.com.au</a> Web: <a href="http://www.caus.com.au">http://www.caus.com.au</a>
Disability Advocacy Resource Unit (DARU)	State-wide	People with all types of disability	Resourcing Advocacy Organisations	VCOSS, Level 8, 128 Exhibition Street Melbourne Victoria 3000 Phone: 03 9639 5807 Email: <a href="mailto:admin@daru.org.au">admin@daru.org.au</a> Web: <a href="http://www.daru.org.au">http://www.daru.org.au</a>
DisAbility Connections (Victoria) – formerly Western Region Disability Network	North and West Metropolitan region	Anyone who shares a passion for disability issues	Information and Systemic Advocacy Service	81 Cowper Street Footscray Victoria 3011 Phone: 03 9687 7066 Email: <a href="mailto:dcvteam@annecto.org.au">dcvteam@annecto.org.au</a> Web: <a href="http://www.disabilityconnections.org.au/">http://www.disabilityconnections.org.au/</a>

<b>State funded agency</b>	<b>Service Area</b>	<b>Specialisation</b>	<b>Services provided</b>	<b>Contact details</b>
Disability Discrimination Legal Service Inc. (DDLS)	State-wide	People with all types of disability	<ul style="list-style-type: none"> <li>• Information</li> <li>• Referral</li> <li>• Advice</li> <li>• Casework assistance</li> <li>• Community legal education</li> <li>• Policy and law reform</li> </ul>	Ross House 2nd Floor, 247 Flinders Lane Melbourne Victoria 300 Phone: 03 9654 8644 TTY: 03 9654 6817 Email: <a href="mailto:info@ddls.org.au">info@ddls.org.au</a> Web: <a href="http://www.communitylaw.org.au/ddls/">http://www.communitylaw.org.au/ddls/</a>
Disability Resource Centre - Head Office	Metropolitan Melbourne	People with all types of disability	Individual advocacy	179 High Street Northcote Victoria 3070 Phone: 03 9481 6646 Email: <a href="mailto:info@drc.org.au">info@drc.org.au</a> Web: <a href="http://www.drc.org.au">http://www.drc.org.au</a>
Disability Resource Centre - Outer Southeast Outreach Service	LGAs of Casey, Cardinia, Dandenong, Frankston, Mornington Peninsula and Kingston	People with all types of disability	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Training in self advocacy</li> </ul>	186 Foster Street East Dandenong Victoria 3175 Phone: 03 9791 4870 Email: <a href="mailto:katrina@drc.org.au">katrina@drc.org.au</a> Web: <a href="http://www.drc.org.au">http://www.drc.org.au</a>
Disability Rights Victoria	State-wide	People with all types of disability	Individual advocacy	179 High Street Northcote Victoria 3070 Phone: 03 9489 2999 Email: <a href="mailto:drvic@afcl.org.au">drvic@afcl.org.au</a>
Inclusive Leisure Initiative	State-wide	People with disabilities, their carers and advocacy groups in relation to recreation, sport, physical activity, tourism and the arts.	Information and advocacy network	86-88 High Street Northcote Victoria 3070 Phone: 03 9489 2999 Email: <a href="mailto:acl@afcl.org.au">acl@afcl.org.au</a> Web: <a href="http://www.aquaticsandrecreation.org.au/inclusiveleisureinitiative">http://www.aquaticsandrecreation.org.au/inclusiveleisureinitiative</a>

<b>State funded agency</b>	<b>Service Area</b>	<b>Specialisation</b>	<b>Services provided</b>	<b>Contact details</b>
Migrant Resource Centre North West Region	North and West Metropolitan region	People with a disability from ethnic backgrounds	Individual advocacy	45 Main Road West St Albans Victoria 3021 Phone: 03 9367 6044 Email: <a href="mailto:mrcnw@northwest.org.au">mrcnw@northwest.org.au</a> Web: <a href="http://www.mrcnorthwest.org.au">http://www.mrcnorthwest.org.au</a>
Office of the Public Advocate (OPA)	State-wide	Promotes and protect the rights, interests and dignity of people with disabilities	<ul style="list-style-type: none"> <li>• Advice</li> <li>• Investigation</li> <li>• Individual advocacy</li> <li>• Guardianship services</li> </ul>	5th Floor, 436 Lonsdale Street Melbourne 3000 Victoria 3000 Phone: 1300 309 337 Web: <a href="http://www.publicadvocate.vic.gov.au">http://www.publicadvocate.vic.gov.au</a>
Reinforce Inc	State-wide	People with an intellectual disability	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Peer support for self advocacy</li> </ul>	2nd Floor, Ross House 247-251 Flinders Lane Melbourne Victoria 3000 Phone: 03 9650 7855 Email: <a href="mailto:reinforce@rosshouse.org.au">reinforce@rosshouse.org.au</a> Web: <a href="http://www.reinforce.org.au">http://www.reinforce.org.au</a>
Self Advocacy Resource Unit (SARU)	State-wide	People with an acquired brain injury, people with an intellectual disability and with high communication needs	Supporting and resourcing self advocacy groups	Ross House, Level 1, 247 Flinders Lane Melbourne Victoria 3000 Phone: 03 9639 6856 Email: <a href="mailto:saru@rosshouse.org.au">saru@rosshouse.org.au</a> Web: <a href="http://www.saru.net.au/">http://www.saru.net.au/</a>
STAR Victoria Inc.	State-wide	People with an intellectual disability and their families	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Systemic advocacy</li> </ul>	Ross House, 2nd Floor 247 Flinders Lane Melbourne Victoria 3000 Phone: 03 9650 2730 Email: <a href="mailto:info@starvictoria.org.au">info@starvictoria.org.au</a>

State funded agency	Service Area	Specialisation	Services provided	Contact details
				Web: <a href="http://www.starvictoria.org.au">http://www.starvictoria.org.au</a>
VALID Inc. (Victorian Advocacy League for Individuals with a Disability)	State-wide	People with intellectual disabilities, their families, carers and advocates	<ul style="list-style-type: none"> <li>• Individual advocacy</li> <li>• Training in self advocacy</li> </ul>	235 Napier Street Fitzroy Victoria 3065 Phone: 03 9416 4003 Email: <a href="mailto:office@valid.org.au">office@valid.org.au</a> Web: <a href="http://www.valid.org.au">http://www.valid.org.au</a>
Victorian Council of Deaf People Inc.(VCOD)	State-wide	The deaf community	Individual advocacy	PO Box 6186 St Kilda Rd Melbourne Victoria 3004 Phone:133677 (quote TTY number 03 9521 2466) Email: <a href="mailto:admin@vcod.com.au">admin@vcod.com.au</a> Web: <a href="http://www.vcod.com.au/">http://www.vcod.com.au/</a>
Victorian Disability Advocacy Network (VDAN)	State-wide	Coalition of independent, community based disability advocacy organisations	Peak body	Email: <a href="mailto:vdan@vdan.org.au">vdan@vdan.org.au</a> Web: <a href="http://www.vdan.org.au/">http://www.vdan.org.au/</a>
Women with Disability Victoria (Formerly WWDN)	State-wide	Women with disabilities	Systemic advocacy and information service	GPO Box 1160 Level 8/255 Bourke St Melbourne Victoria 3000 Phone: 03 9662 3755 Email : <a href="mailto:wdv@wdv.org.au">wdv@wdv.org.au</a> Web: <a href="http://www.wdv.org.au">http://www.wdv.org.au</a>
Yooralla	State-wide	Children and adults who have acquired disabilities through road and recreational accidents, health problems, drug and alcohol abuse, and the effects of ageing, as well as people who are born with disabilities	Service provider with an advocacy arm for their client group	Level 2, 244 Flinders Street Melbourne Victoria 3000 Phone: 1300 9667 2552 Email: <a href="mailto:ooralla@ooralla.com.au">ooralla@ooralla.com.au</a> Web: <a href="http://www.yooralla.com.au/">http://www.yooralla.com.au/</a>
Youth Disability Advocacy	State-wide	Young people with disabilities	Individual advocacy	Level 2, 180 Flinders St

State funded agency	Service Area	Specialisation	Services provided	Contact details
Service (YDAS)		between the ages of 12 and 25		Melbourne Victoria 3000 Phone: 03 9267 3733 Email: <a href="mailto:ydasmanager@yacvic.org.au">ydasmanager@yacvic.org.au</a> Web: <a href="http://www.ydas.org.au">http://www.ydas.org.au</a>