Research of the Models of Advocacy Funded under the National Disability Advocacy Program

Appendices to the Final Report

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Review of the Research Literature
Appendix A
Research of the Models of Advocacy Funded under the National Disability Advocacy Program

Review of the Research Literature

This review of the research literature was undertaken as part of a project to research the models of advocacy funded under the National Disability Advocacy Program. A search of various social and psychological research databases, the Internet and library collections was conducted with the assistance of a specialist disability library. The identified research articles, reports, reviews and Internet sites were then reviewed by the research team from Jenny Pearson & Associates Pty Ltd.

The aims of this review of the research literature were to:

- analyse Australian and international research findings in relation to advocacy models of support for people with a disability
- review research findings regarding the appropriateness, effectiveness and efficiency of different advocacy models or combinations thereof
- consider how overseas models of advocacy can apply to the Australian context and how the models compare with those funded under the NDAP.

This review paper is structured as follows:

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Defining Advocacy

Cocks and Duffy use Wolfensberger’s definition of advocacy in their 1993 monograph presenting the results of the National Advocacy Research Project, i.e. 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 and defend the welfare of, and justice for, either individuals or groups, in a fashion which strives to be emphatic and vigorous.

(Wolfensberger, 1992 cited by Cocks & Duffy 1993, pp.41-42)

Martin (2003) writes that ‘advocacy involves taking action in defence of a person’s interests’ and ‘may involve the advocate taking direct action, trying to get others to take action, or helping the person to develop skills for personal achievement’. (p.15)

In simpler terms, Parsons (1994) suggests:

Advocacy is essentially the very ordinary process of standing up for the rights of people who are being treated unfairly. (p.10)

Parsons goes on to explain that despite its ordinariness, advocacy is rarely easy.
Models of Advocacy Described in the Research Literature

There is a myriad of advocacy models, definitions and classifications in the international research literature. Up to seventeen different types of advocacy have been described in one publication (Advocacy, a Rights Issue, cited by Weafer, 2003).

Taking a broader view, Weafer (2003) suggests two main divisions of advocacy: one where the person or group represents themselves or those in a similar situation to themselves, and the other where an external person represents the individual or group. Weafer suggests that the first type of advocacy emphasises empowerment, while the second tends to emphasise the expertise or skills of the external advocate.

Cocks and Duffy describe three approaches to advocacy for people with disabilities based on Wolfensberger’s work:

1. Informal/normative approaches to advocacy (e.g. family members or friends standing up for another family member or friend who is being treated unfairly).
2. Advocacy within human service systems (e.g. when the state acts as advocate, independent public advocacy programs, non-independent advocacy programs, public interest advocacy).
3. Legal advocacy.

Hutchison, Arai, Pedlar, Lord & Yuen (2007) distinguish between:

- non-user-led disability organisations where leadership is primarily provided by professionals or families, without a strict mandate to include a significant number of people with disabilities; and
- user-led disability organisations where the leadership is provided primarily by people with disabilities and there are strict user-led governance structures.

Hutchison et al describe the growing role of user-led disability organisations and the role of these organisations in systemic advocacy and increased participation by people with disabilities in policy-making.

Much of the research literature in respect of specific models of advocacy focuses on Self Advocacy and Citizen Advocacy.

Self Advocacy

Defining Self Advocacy

Merchant and Gajar (1997) define self advocacy as:

. . . an individual’s ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions.’ (p.223)

Pennell (2001) offers a more inspirational definition:

Self-advocacy means helping people understand that we are all “able” and empowering people to take control over their own lives to make decisions and take the consequences. Self-advocacy is a process – a way of life that is an ongoing learning experience for everyone involved. It means taking risks and
going after your dreams. It means making mistakes and learning from them. Self-advocacy is a revolution for change, to enable people with and without disabilities to live in harmony. Self-advocacy is founded on the belief that together, we can create the spark to light the fire of a better life for all of us. (p.223)

Bramley & Elkins (1998) refer to a definition by Rhoades that describes self-advocacy as a social movement organised and controlled by people with intellectual disability assisted by non-disabled advisors.

Weafer (1993) cites a list of five broad categories of self-advocacy groups for people with intellectual disability proposed by Simons (1992):

- discussion groups in adult education
- groups based in services (typically comprising 8-12 members, meeting once a month in centre premises with a staff member or independent outsider performing the role of advisor/facilitator)
- independent groups
- divisional groups (sub-sections of an existing organisation, most common in the USA)
- coalition groups (involving an alliance between people with different disabilities).

Weafer notes that service-based groups are the most common form of self-advocacy in Ireland.

McNally (1999) writes that self-advocacy is ‘about people speaking for themselves and asserting their own rights, individually and in groups which share a common interest or face particular difficulties, for example stigma’. (pp.47-48) McNally cites the core components of self-advocacy identified by Clare (1990), i.e.

- being able to express thoughts and feelings with assertiveness if necessary
- being able to make choices and decisions
- having clear knowledge about rights
- being able to make changes.

McNally adds that any act of self-determination or choice can be viewed as self-advocacy. The terms self-advocacy and self-determination are often used interchangeably or one may be viewed as a skills subset of the other. (Wehmeyer, Bersani & Gagne, 2000)

Sutcliffe and West (1998) describe self-advocacy as complex and diverse, operating in wide range of contexts and with many forms (citing Sutcliffe and Simons, 1993).

Downer and Ferns (1998) write that a self-advocacy group has to:

- ‘be independent of services and workers
- have funding without any strings attached
- be controlled by people with learning difficulties
• be advised by experienced disabled people and/or non-disabled people skilled in enabling self-advocacy
• not be shaped by outside expectations of non-disabled people
• be given space and time to grow and develop
• be built on the strengths of the group members
• be taken seriously by services which should not pretend to support self-advocacy when they really do not
• have their advice and decisions listened to carefully and acted upon by service workers
• have real power and representation in important decisions about services which affect users’ lives
• become a pressure group for positive change in services
• empower group members to change their own lives with the support of other disabled people’. (pp.144-145)

As can be seen from the research literature, self-advocacy in the international context is often a group model and in many cases, exclusively for people with intellectual disability.

**History of Self Advocacy Around the World**

Self advocacy originated in Sweden in the 1960s when leisure clubs established for people with intellectual disability formed member committees which then met nationally. The international self advocacy movement, *People First*, began in the United States in 1973/74. The American Coalition of Citizens with Disabilities was also formed in 1974. Self advocacy in the United Kingdom began in 1984 with the founding of a People First group in London Boroughs. Speaking up events had started as early as 1972. The number of self advocacy groups continued to grow through the 1980s. (McNally 1999; Buchanan & Walmsley, 2006; Bramley & Elkins, 1998)

The People First movement in the United States became an incorporated body in 1981. An elected Board of Directors was responsible to the local chapters which met together periodically to share ideas and information or organise state workshops or regional seminars. Each state held an annual convention with a national convention every four years. (Bramley & Elkins, 1988)

Pennell (2001) describes the development of self-advocacy in an environment in the United States where the philosophies and practices of normalisation, inclusion and person-centred planning had emerged. Pennell goes on to describe the evolution in the 1990s of these themes into the philosophy of self-determination which focuses on ‘reforming systems to provide greater opportunities for choice and self-direction and on providing people with disabilities with skills and information so they can express self-determination in their own lives’. (p.223)
In Wales, the All Wales Strategy (AWS) required that representatives of people with learning disabilities\(^1\) be involved in the planning, management and review of services for ‘mentally handicapped’ people. The number of self advocacy groups grew markedly following implementation of the AWS from just two groups in 1985 to 58 groups a decade later. (Whittell & Ramcharan, 1998a)

Whittell and Ramcharan (1998b) describe the strong link between self advocacy and community adult education in Wales. Some of the first self advocacy groups in Wales met in adult education centres and the facilitators were trained by an institute for higher education. Since 1994, the community education self advocacy groups have been funded through local colleges.

In Ireland, Weafer (1993) writes that self advocacy groups have grown up in organisations for people with intellectual disability and among mental health service consumers.

In Denmark, sports clubs for people with intellectual disability evolved into self advocacy organisations known as ‘Culture Conferences’ which conducted demonstrations and undertook other political action to influence public policy. From the first Culture Conference in 1987 which was supported by a parents’ organisation, Culture Conference meetings by the 1990s involved several hundred people with intellectual disability learning about their rights and taking a position on disability policies. (Bersani, 1998)

Bersani (1998) considers that ‘self advocacy represents a new social movement with history, principles, organisation, conceptual reform, language, solidarity, justice and alliances’. (p.63)

The first officially acknowledged self-advocacy group for people with intellectual disability in Japan was established in 1990. There is now a growing network of self advocacy groups across the country, including People First organisations and a range of recreational and educational groups. By 2004, Inclusion Japan reported that there were 142 self-advocacy groups in Japan. (Tsuda, 2006)

Key self advocacy events in Japan include: a self advocates’ meeting at the annual national conference held by Inclusion Japan; seminars organised by Inclusion Japan for self advocates and advisors; and a national People First conference held every year.

At the Inclusion Japan national conference, delegates attending the self advocates meeting discuss various themes and resolve an agenda with topics including: participation in the political process; reduced fares on public transport to facilitate social inclusion; simple ID cards, service information; and building a safe community. (Tsuda, 2006). Tsuda notes that a research survey conducted by Mitsumasu and Honma in 1997 found that one third of self advocacy groups in Japan were advised by parents or a parents’ organisation.

\(^1\) The term ‘learning difficulty’ or ‘learning disability’ is often used in place of ‘intellectual disability’ in countries such as the United Kingdom. Intellectual disability is the term adopted by the World Health Organisation. (Ward, 1998)
Examples of self advocacy in New Zealand include a national consumer network in the area of mental health, a People First New Zealand organisation and an internal self advocacy team within IHC, a traditional service organisation for people with intellectual disability. This internal self advocacy team employs self advocacy coordinators to strengthen the ability of people who use IHC services to communicate, be heard at branch committees and to provide training on self advocacy to staff and people with intellectual disability. The internal self advocacy group has advocated for change to proposed legislation and for the closure of an institution for people with intellectual disability. (O’Brien, 2004)

Siska (2006) describes the development of self advocacy in the Czech Republic. After volunteering as a support worker in self advocacy meetings in the United Kingdom, Siska returned to the Czech Republic in 1997 and approached a parent-led group of approximately 15 employees at a sheltered workshop in Prague. At that time, self advocacy was a little known concept in the Czech Republic. This first self advocacy group initially focused on learning communication skills and the original group expanded and the idea of self advocacy spread amongst the new non-government organisations that were providing services for people with disability. The self advocacy group was supported by the national parent organisation which provided meeting rooms and financial support to publish a handbook for self advocates.

As new self advocacy groups were formed, the need for support workers to assist the groups’ development was identified. Since 2004, the European Commission has provided funding for a training program for self-advocates and their supporters via Inclusion Europe. Siska is optimistic about the future of the self advocacy movement in the Czech Republic and in other new member states of the European Union.

In a study of self advocacy in Canada, McColl and Boyce (2003) find that organisations that view people with disability as ‘consumers,’ aim for majority representation of people with disability in all operational aspects and tend to use self help, resist professional involvement, and promote access to resources and training. Organisations that view people with disability as ‘clients’ see their role as speaking on behalf of and in support of people with disability.

The interviewees in the study conducted by McColl and Boyce (2003) described an ideological shift over the previous two decades ‘from service to advocacy, from confrontation to collaboration, and from clients to consumers’. (p.389)

Bramley & Elkins (1988) describe the development of self advocacy in Australia as a fairly recent phenomenon compared to the United States and Europe. The first self advocacy group in this country was established in Victoria in 1981. This was followed two years later by a group in New South Wales and subsequently self advocacy groups in other states which had varying success. Bramley & Elkins consider that the growth of self advocacy groups in Australia has resulted more from government and agency policies in regard to deinstitutionalisation, normalisation and consumerism than from the spontaneous activity of people with intellectual disability. They note that many self advocacy groups have emerged from support groups for people leaving institutions and as a flow-on effect from participation in conferences for people with intellectual disability.
Citizen Advocacy

Wolf Wolfensburger is credited with founding the Citizen Advocacy model. (Tanguay, 1987) In 1966, a group of parents of people with developmental disabilities in America discussed the issue of who would take an interest in their sons and daughters when the parents died. Existing service systems, including paid advocacy services were considered inadequate for this role. In 1968, Wolf Wolfensberger suggested a schema that would not have the conflicts of interest or the lack of individualised attention of other systems.

Wolfensberger recommended a Citizen Advocacy model that should:

- have the potential for long-term continuity of personal relationships between individuals with a disability and other community members
- be separate from service provision
- be as free as possible from conflict of interest
- provide a flexible and wide range of options to meet each individual's needs and wishes
- remain committed to the protection of each individual's interests. (Page-Hanify 1992, p.88)

The first Citizen Advocacy program was established in Nebraska in 1970. Following United States legislation which provided funding for systems to protect and advocate the rights of people with developmental disabilities, approximately 600 Citizen Advocacy programs started, although only about 200 of these survived.

Canada, the United Kingdom and Ireland all now have Citizen Advocacy programs.

Australia's first Citizen Advocacy program was founded in Perth in 1980, with a second program following in Melbourne in 1981. Up to 21 programs existed at the time of Page-Hanify's 1992 paper.

There was a move to establish Citizen Advocacy in New Zealand through the late 1980’s and 1990’s but only one of the three programs has survived. In 2004, this program had approximately 60 people matched for the purposes of social advocacy and instrumental advocacy. (O'Brien, 2004)

There have been several definitions of what Citizen Advocacy is. O'Brien (1987) offers this:

A valued citizen who is unpaid and independent of human services creates a relationship with a person who is at risk of social exclusion and chooses one or several of many ways to understand, respond to, and represent that person's interests as if they were the advocate's own thus bringing their partner's gifts and concerns into the circles of ordinary community life. (O'Brien 1987, p.3)

A more recent definition was agreed in 1990 by the International Citizen Advocacy Group which includes two Australians:

Citizen Advocacy is a means to promote, protect and defend the welfare and interests of, and justice for, persons who are impaired in competence, or diminished in status, or seriously physically or socially isolated, through one-to-
one (or near one-to-one) unpaid voluntary commitments made to them by people of relevant competencies. Citizen advocates strive to represent the interests of the person as if they were the advocate’s own; therefore the advocates must be sufficiently free from conflict of interest. Citizen advocates are supported, and usually recruited, by a Citizen Advocacy Office with paid staff, that is so funded and governed as to be essentially free from conflicts of interest. In consultation with this Citizen Advocacy Office, advocates choose from among a range of functions and roles. Some of these commitments may last for life. (Page-Hanify 1992, p.89)

A simpler definition cited by Hindle (1993) is as follows:

Citizen Advocacy happens when a valued and competent citizen who is unpaid and independent, with the support of an independent Citizen Advocacy office, represents the interests of a person who has a disability as if those interests were her or his own. (p.29)

Hindle writes that the aim of all Citizen Advocacy programs is:

‘to identify people with disabilities to become protégés, to identify people from the local community to become citizen advocates and to support each protégé and citizen advocate in their relationship’. (p.29)

Hindle describes principles adapted from the CAPE (Standards for Citizen Advocacy Program Evaluation, Wolfensberger & O’Brien, 1979) which guide all Citizen Advocacy practice. These standards involve:

- advocate independence
- loyalty to protégés
- program independence
- clarity of staff function
- balanced orientation to protégé needs
- protégé characteristics
- diversity of advocacy roles
- Citizen Advocacy Office effectiveness
- balance of Citizen Advocacy Office activities
- positive interpretations of people with disability
- program continuity and stability
- community leadership involvement.

O’Brien (1987) spells out the following principles on which a Citizen Advocacy program is founded:

- The focus of all of the energy available for the program is on creating and supporting a variety of responsible personal relationships that encourage identification with and active representation of the person with a disability, bring the person with a disability into social and community life, and usually involve long term commitments.
• The CA program purposely seeks diversity among the people it invites into relationships.

• Over time, people will be involved in relationships that can be described in a variety of different ways.

• Citizen advocates freely choose to enter a relationship which is independent of the human service system and not controlled by the CA program. CA relationships are voluntary, but citizen advocates are not ‘volunteers’ to an agency. They find direction in their relationship, not from an outside supervisor.

• Citizen advocates are supported by the CA program but not supervised, evaluated, or fired by the CA program.

• Citizen advocates are not paid or compensated in any way by or because of the program.

• The CA program itself is a model of positive interactions and interpretations of people with handicaps.

• The program defines its identity and develops its support in the community, is able to act independently of the human service system, and is not identified with the human service system. (pp.10-13)

Ward (1986) describes how from the outset, Citizen Advocacy was seen as a way of helping with practical needs and also emotional needs.

The essence of Citizen Advocacy lies in the relationship between the disabled person and the advocate; that relationship being perhaps as much about satisfying emotional needs as with addressing particular practical problems as they arise. That relationship is simply that: a relationship like any other that must take its course. Once established it will be a relationship free of any control even by the Citizen Advocacy Office. (Ward 1986, p.91)

Weafer (2003) writes that the citizen advocate’s role has two aspects: representative and social, although the representative role is seen as more important.

Ward (1986) stresses that the advocate’s primary loyalty is to the person with a disability and not to the Citizen Advocacy Office. Ward attributes the power of citizen advocacy to this independence.

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, p.93)

Ward also considers that citizen advocates derive power from being a non-professional and not being a relative of the person with a disability.

Various authors identify a number of advantages or potential strengths of citizen advocacy: Refer to Table 1.
Table 1 Advantages of Citizen Advocacy identified in the Research Literature

<table>
<thead>
<tr>
<th>Advantage Cited</th>
<th>Author Reference</th>
</tr>
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<tbody>
<tr>
<td>Citizen advocates are ‘free agents’</td>
<td>Tanguay, 1987</td>
</tr>
<tr>
<td>Volunteers are not afraid of losing their job</td>
<td>Tanguay, 1987</td>
</tr>
<tr>
<td>Citizen Advocacy is separate from direct services and from a casework or paid protective services worker approach.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>Citizen Advocacy offers reasonable probabilities for continuity of protection and advocacy, due to the back-up of volunteer advocates by paid staff.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>Built-in conflicts of interest are as low as any organised helping form can make them.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>There is a highly individualised range of advocacy options to meet instrumental, expressive, and instrumental-expressive needs.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>Most needs can be met through informal relationships. The option also exists for citizen advocates to assume formally recognised roles (e.g. guardianship) when it is required by the person with a disability.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>There is a reasonable chance that long-term relationships can exist either formally or informally.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>The cost of Citizen Advocacy is low, especially in comparison to full-time paid protective service workers.</td>
<td>Forrest, 1986</td>
</tr>
<tr>
<td>‘The long-term nature of citizen advocacy partnerships offers the potential for developing self-confidence and opportunities with those who may have experienced exclusion over many years.’</td>
<td>Weafer, 2003, p.42</td>
</tr>
</tbody>
</table>

Legal Advocacy
Ward (1986) defines legal advocacy as: ‘any advocacy done by a lawyer on behalf of a client to resolve an issue or solve a problem for that client’. (p.92) Ward goes on to point out that the lawyer will be paid for his/her work, will only act in accordance with his/her client’s wishes and will speak for his/her client even where this means taking a point of view on behalf of the client which does not concur with his/her own views.

Weafer (2003) describes Legal Advocacy as ‘the most widespread form of advocacy, especially in North America’.

In Canada, the main form of government-funded legal advocacy is provincially-based legal aid which is available to people on limited incomes. This form of legal support is...
not related to disability and the lawyer provided may or may not be experienced in disability issues. The Federal government in Canada provides some funds through a Court challenges program that deals with legal and human rights issues, such as discrimination against people with disability. There are eligibility criteria and rules limiting access to these funds and they are consequently underutilised. (Uditsky, 2004).

There is one legal advocacy service specifically for people with disability in New Zealand (Justice Action) and the only other recourse is to generic services such as legal aid. (O’Brien, 2004)

Hayes (1998) argues the case for legal advocacy support for people with disability, particularly those with learning/intellectual disability in the criminal justice system. Hayes cites research findings that:

- nearly one quarter (23.6 per cent) of people appearing before six local courts in New South Wales had a standard IQ score of 70 and would meet the diagnostic criteria of intellectual disability and a further 14 per cent obtained a standard IQ score of between 70 and 79 and were thus in the borderline range
- more than one third (35.6 per cent) of the sample in the same study fell below the cut-off point on the Mini-Mental State Examination, indicating a need for further psychiatric assessment
- if an accused person with intellectual disability is not legally represented, there is a greater chance that their disability will not be recognised during the criminal proceedings and that appropriate legal protections will not be implemented
- during police questioning, people with intellectual disability may be more vulnerable than non-disabled interviewees because they are more likely to acquiesce and answer questions in the affirmative and to be misled by leading questions
- of those suspects who are questioned by police, people with an intellectual disability are more likely to proceed to a court appearance.

A review of legal services available to people with disability in New Zealand undertaken by Diesfield, Patston, McLean, Miller-Burgering and Vickery (2006), identified a range of barriers for people with disability needing to access legal services. These barriers included limited knowledge of legal services; inaccessible legal services, lack of understanding and knowledge of disability issues amongst lawyers and advocates, complexity of the legal system, and lack of knowledge about rights. The researchers concluded that:

- ‘People in the legal system still lack adequate awareness of the diverse needs of people with a wide range of impairments and legislative changes often create unintended consequences for disabled people.’ (p.1)
- (Legal) ‘Services need to be skilled to anticipate and provide: alternatives to print materials (e.g. plain English, Braille, large print, web pages designed to be accessible for audible text); alternatives to spoken word (e.g. New Zealand sign language and video relay service for the Deaf, speech synthesiser for someone with a speech impairment, cultural mediation); assistance in understanding the legal system (e.g. to ensure that some clients do not misinterpret non-verbal nuances, seek to please people in authority, or agree to a suggested course of
action that may be to their detriment); accessible premises (e.g. accessible parking, entrances, toilets) so that clients can attend legal services.’ (p.1)

• People with disability cited lack of knowledge about their rights, complexity of the legal system, fear of repercussions and fear of costs.

• Some lawyers representing people subject to compulsory treatment orders were viewed as neither independent nor expert in disability law.

• Some personnel in community law centres were viewed as lacking adequate knowledge of mental health and other disability issues.

• ‘For some informants, legal aid was characterised as a “lucky dip”.’ (p.2)

• Legal informants to the research acknowledged a range of challenges in providing legal service to people with disability including the complexity of serving clients with dual diagnoses (e.g. mental illness and intellectual disability), overlap between disability and legal issues, inadequate legal advocacy mechanisms for people with disability, complexity of the field of disability law, and the need for increased expertise within the legal profession.

Family Advocacy

Family advocacy is an independent, community-based model that usually involves family members acting on behalf of a son or daughter or sibling. (Weafer, 2003, p.39)

Bane (1998) reports on a system of Family Advocacy Coordinators (known as ‘Family Advocates’) developed in Colorado to strengthen family involvement at local and state levels. The Family Advocates occupy paid positions and are usually parents or family members of children or adolescents who are current or former consumers of some aspect of the local services system. This model recognises the need to have families represented in policy and service development and emphasises organising family support and advocacy networks.

This family advocate program began in the state mental health system and later expanded to include juvenile justice and child welfare systems. The family advocates are integrated with interagency councils and service coordination teams. Bane (1998) notes that the activities of the Family Advocates include attending Individualised Education Program meetings, developing support groups, providing individualised supports to families and participating in local interagency councils and advisory groups.

Citing the findings of a recent evaluation, Bane (1998) reported that ‘the availability of a Family Advocacy Coordinator favourably influences a family’s perception that their child’s service needs are met’. (p.11) Bane also found that Family Advocates can increase the effectiveness of other more traditional methods of assisting families.

Families of children with mental health needs often find themselves involved with various systems, or wondering where to access help. Family Advocates can offer a bridge for families needing information and a guide to help them obtain the support they need. (Bane, 1998, p.12)

In Canada, the longest standing and strongest organised advocacy is by families of individuals with intellectual disability. Uditsky (2004) identifies a number of strengths in
this movement, including its vision, values and freedom to exercise these independent of government funding.

**Group Advocacy**

Weafer (2003) describes group advocacy or collective advocacy as involving 'a group of people campaigning on behalf of themselves or others to try and change things'. (p.37)

Other authors refer to 'collective advocacy' where a core group represents the interests of a larger group. (Rapaport et al, 2006)

Tanguay (1987) defines group advocacy in the context of a citizen advocacy model:

> Group advocacy is the collective action of individual advocates, each with his/her own protégé. Such action is taken to secure improved service for their protégés, who have either the same need, or different needs, such as loneliness, special diets, etc. but who all live in the same facility. (p.2)

**Peer Advocacy**

Peer advocacy occurs where a person with a disability acts as an advocate for someone else with a comparable disability (Uditsky, 2004).

> The person advocating works with, supports or represents someone whose difficulties are similar to those the advocate has experienced him/herself in the past. (Wefer, 2003, p.37)

Uditsky describes this model of advocacy in Canada but notes a weakness in the model assuming that a person will be a competent advocate with an appropriate values base simply by virtue of having a disability. Uditsky also refers to family to family or parent to parent advocacy as another form of peer advocacy and states that this concept of advocacy is 'the backbone of the family advocacy movement in Canada for individuals with intellectual disability'. (p.27)

Peer advocacy is also acknowledged as a core type of advocacy by Rapaport et al (2006). Weafer (2003) notes that this was the dominant early model of advocacy in mainstream psychiatry.

**Systemic Advocacy**

In the Australian context, Seymour and Peter (2004) provide a simple definition of systems advocacy:

> . . . systems advocacy lobbies for reform and change of social systems and structures that discriminate against, abuse and neglect people with disabilities. (p.12)

Seymour and Peter note that systems advocacy 'can only address issues over a long, strategic and sustained campaign of change'. (p.12)

There is little in the way of formal research on the nature of systemic advocacy.
Interviews conducted by McColl and Boyce with 17 key informants who had been involved in significant policy initiatives in Canada, found repeated reference to five fundamental advocacy issues for disability advocacy groups:

- housing
- education
- employment
- transportation
- human rights.

There are some reports of programs and initiatives designed to assist people with disability and their associates to influence public policy.

*Partners in Policymaking* is a leadership training program for individuals with disability and parents of young children with disability. The program provides 128 hours of instruction over eight weekends with a session held one weekend each month. The program was first established in Minnesota in 1987 when a leadership vacuum and a need for parents and self-advocates to learn how to make effective systems change was identified. (Barenok & Wieck, 1998) Balcazar, Keys, Bertam and Rizzo (1996) report that this program has shown encouraging results and their study found that all participants benefited from involvement in the advocacy training, although previous experience as an advocate and membership in advocacy organisations were significant predictors of the overall advocacy performance of the participants after completion of the program.

National speakers deliver the training and a coordinator manages the program logistics and other arrangements. Two broad topic areas are covered by the program curriculum:

- life area topics, for example, best delivery practices, inclusive education, assistive technology and positioning, competitive employment, independent living and a home of your own
- policy and systems topics which introduce participants to working with federal, state and county officials and teach them how to access policymakers through writing letters and providing testimony.

Partners in Policymaking learning methods include role playing, group activities and small group discussions. The program has a commitment to quality improvement and undergoes long term evaluations by external evaluators, self evaluation by program coordinators, evaluation by the funding source and presenter evaluation by participants after each session.

As at 1998, Partners programs were operating or being planned in forty two states in the USA, six sites in the United Kingdom and a UNICEF-funded program in the Philippines. (Barenok & Wieck, 1998)

The New Zealand CCS, an organisation which provides services for people with physical disability, has promoted public advocacy on issues including accessible environments and inclusive education, and has lobbied for disability policy that is consistent with human rights legislation and New Zealand’s Disability Strategy. (O’Brien, 2004)
The Disabled People's Assembly in New Zealand describes itself as a national umbrella organisation and the national voice of people with disability. DPA has advocated on issues such as value of life, human rights, treaty partnership and legislation with priority areas of education, employment, income, disability support services, accommodation, transport, personal health, advocacy awareness, access to information and access to physical environment. (O’Brien, 2004)

Other Models of Advocacy
An accredited training package on Advocacy and People with Disabilities developed in South Australia lists and defines several models of advocacy including individual advocacy (any advocacy provided on behalf of an individual), self advocacy (which is often individual but can also be group advocacy), peer advocacy (advocacy by a member of a peer group), group advocacy, family advocacy, citizen advocacy, legal advocacy (any advocacy related to matters of law) and systems advocacy. (Disability Action, 1997)

Several authors describe further models of advocacy. For example:

- 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. This is sometimes described as ‘crisis advocacy’. (Weafer, 2003)

- Social Support Advocacy: an 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. (Alper, Schloss & Schloss, 1996)

- Interpersonal Advocacy: direct interactions by family members, professionals or others on behalf of a person with disability (particularly a child or youth). (Alper, Schloss & Schloss, 1996)

- Community Advocacy: community advocates typically work within the community on specific issues, for example, a model of community advocacy developed by the Equality Authority and the Irish Traveller Movement to assist travellers to access their rights. (Weafer, 2003)

- Patient Advocacy: patient advocates are generally paid and independent of the institution in which they are based. They may provide information and on-the-spot help for patients, their families and carers. There are quite extensive patient advocacy programs in the Netherlands, Austria and the United Kingdom. (Weafer, 2003)

- Public Policy Advocacy: ‘the effort to influence public policy through various forms of persuasive communication’. (Weafer, 2003) This model is consistent with what would be referred to as Systemic Advocacy in Australia.

- Client Support and Representation Model (CSR): where social workers employed in mental health services take on the advocacy roles of mentor, coach, supporter and representative to assist clients with psychiatric disability to understand and define own their needs, define what action they want to take to fulfil these needs, and take action with the support of an advocate. (Moxley & Freddolino, 1994)
Effectiveness of Advocacy

Boyce et al (2001) attribute the trends in the last two decades toward community living and de-institutionalisation of people with disability; educational integration of people with disability; and support for competitive employment rather than sheltered employment, to the participation and advocacy of groups that represent the interests of people with disability. (cited by McColl & Boyce, 2003)

Amidst this background of success, there are also concerns about the effectiveness of advocacy. These criticisms include:

- inadequate strategic planning by disability groups
- unclear definition of their desired endpoint
- failure to integrate their issues in the larger social context (Todd et al 2000; Bickenbach 1993; Holt et al 2000)
- underfunding and understaffing of disability advocacy (Boyce et al 2001)
- lack of shared issues amongst the disability community, beyond the general issues of access and equity (Crichton & Jongbloed, 1998) – all cited by McColl and Boyce (2003).

McColl and Boyce (2003) suggest that disability advocacy groups need greater numbers, more explicit identity, more focused policy concerns, better resource bases and better communication networks.

Funding

Funding conditions and short term grants can have negative impacts on the effectiveness of disability advocacy by creating uncertainty for the organisation, diverting the organisation from its purpose, increasing staff turnover and increasing bureaucratisation. (McColl and Boyce, 2003, citing Shragge, 1990; Ng, 1990; Rapaport, Manthorpe, Hussein, Moriarty & Collins, 2006)

Rapaport et al (2006) suggests that although funding from statutory sources is vital to advocacy, this funding relationship may threaten the independence of advocacy schemes in challenging public services.

Leadership

Leadership is also identified as an important factor for success. ‘Sometimes one energetic individual in a leadership position made things happen on behalf of an organisation.’ (McColl and Boyce, 2003, p.388). McColl and Boyce also refer to Balcazar et al (1994) who reported that leaders in disability advocacy organisations have markedly affected the issues raised, actions taken and outcomes achieved.

A survey of people with physical disability serving in leadership roles within disability organisations in Canada and the United States has found that those who participated in advocacy activities were significantly more likely to feel that their action improved access to health care resources, attendant care resources and social services. (Jurkowski, Jovanovic & Rowitz, 2002)
Success Factors
Research by Boyce (1998) identifies four conditions that are necessary for successful policy participation by disability advocacy:

- expertise and experience in the advocacy role
- organisation structure that permits efficient resource allocation and coordination
- a distinct and recognisable organisational identity
- leadership that is sufficiently autonomous to be able to act in a timely manner.

(cited by McColl & Boyce, 2003, p.389)

An evaluation of ten advocacy projects in America using a range of individual, self, legal and systemic advocacy approaches has 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 enhanced 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 cost per case for people with developmental disability was higher overall than the cost per case for people with mental illness
- the advocacy agency personnel wage rates and non-personnel costs were especially low when compared to other legal and human service agencies.

(quoted by Bradley, 1983)

Bradley concludes that more research should be conducted into the process and outcomes of a range of advocacy interventions, a single funding source would result in the maximum stability and coherence for advocacy services, and advocacy services should be legitimised in state statute and/or regulation.

Kendrick suggested that the presence of different types of advocacy does not necessarily result in conflicts between them. Rather, Kendrick wrote:

The advantage of the wealth of advocacy options available to many persons with disabilities in the United States, is that they can quite pragmatically get the kind of advocacy they want, including using both peer and non-peer advocates simultaneously. (Kendrick, 2004, p.88)

Parsons also supported the availability of a range of advocacy types.

. . . it will very often be the case that a whole range of forms or types of advocacy will be equally valid, and will need to co-exist, in the one situation. It is rarely the case that anyone, faced with some injustice or inequity in their lives, requires only one strategy, only one form of support to remedy the matter. (Parsons, 1994, p.13)
In order to be effective, Parsons considers that advocacy organisations need to develop strategic links and networks with one another and with other relevant movements for social change. Parsons suggests that flexibility and adaptability of networks and structures amongst advocacy organisations is vital.

**Cost Effectiveness**
The research literature lacks any detailed analysis of the comparative cost effectiveness of different advocacy models. This is probably due to the complexities that would be involved in such a study which would have to address issues such as different accounting systems, varying methods of allocating overhead costs and multiple funding sources.

There is a large body of literature regarding the effectiveness of self advocacy and citizen advocacy and key findings from this research are presented below.

**Effectiveness of Self Advocacy**

**Outcomes and Benefits of Self Advocacy**

Belonging to a self advocacy group has collective and individual benefits for people. At a collective level, the voice of people with learning disabilities is being heard, listened to and taken seriously in many places and their representation on various groups and committees is now well established. Learning how to speak up and belonging to a self advocacy group also gives individuals more confidence. (Whittell & Ramcharan, 1998b, p.45)

Bersani (1998) attributes some important policy and legislative changes that have occurred as a result of action by self advocates. One example cited by Bersani was the case involving a woman with intellectual disability known as ‘Eve’, with the efforts of the People First movement in Canada credited with achieving a Supreme Court ruling that no-one will be sterilised without their permission. (citing Kappel, 1996) Other examples involved the closure of institutions.

McNally (1999) notes that although 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.

**Individual versus Group Outcomes**

Test et al (2005) and Pocock et al (2002) report that a large number of research studies have identified the effectiveness and benefits of teaching self advocacy skills to students with intellectual and other disability.

Balcazar et al (1996) find that participants in the *Partners in Policymaking* advocacy training program for people with developmental disability and their family members increase their advocacy actions and experience other benefits such as developing a sense of comradeship with other participants, becoming more knowledgeable about the services available to them and gaining more access to these services.

Seymour and Peter (2004) agree that teaching people the skills of self-advocacy results in improvements to self-esteem and self worth. These authors write that: ‘Self advocacy
is frequently a liberating and empowering experience for the advocates’. (p.11) Seymour and Peter add that the process of self advocates telling their story can also have a strong effect on people who do not have a disability and that this can be a catalyst for change. Despite the effectiveness of self advocacy for the individuals involved, Seymour and Peter question the effectiveness of self advocacy in protecting other people with disability.

Buchanan & Walmsley (2006) describe ‘an inherent tension between individuals using self-advocacy groups as a mechanism to gain confidence and skills in speaking up, and self-advocacy organisations campaigning for change on behalf of the collective’. (p.134) The authors go on to explain the reason for this:

Self advocacy as a means of individuals gaining confidence requires a continual process of inducting new members, whereas if they are to be effective campaigning organisations, self-advocacy groups need people with experience and sophisticated skills in debate and management of budgets and people. These do not sit easily together. (p.134)

Dowse (2001) sees this dichotomy as a complimentary relationship with Self Advocacy having two simultaneous aspects: ‘a practice for individuals to utilise to contest oppressive practices and structures within the social world’ and a recognition that ‘Self Advocacy represents the interests of all people with learning disability in a collective endeavour’. (pp.130-131)

**Limitations of Self Advocacy**

Parsons (1994) warns against seeing self advocacy as the only real means by which people with disability can become empowered. Parsons suggests that such an exclusionary approach could lead to people with disability missing out on many other forms of advocacy which ‘even people less powerless would call on from time to time’. Nevertheless, Parsons stresses that self advocacy can, does and should play an important role in the empowerment of people with disability.

Buchanan and Walmsley (2006) note a number of limitations to the models of self advocacy in England:

- self advocacy organisations may neglect concrete issues in favour of arguments about inclusive processes
- self advocacy that is now funded by local government is subject to the same conditions as other services, i.e. funding contracts, targets and deadlines
- self advocacy has become ‘part of the panoply of Government’.

Buchanan & Walmsley (2006) suggest that rivalry between self advocacy organisations has contributed to difficulties in establishing a national organisation for self advocacy in England, although this has been achieved in European and other UK countries.

In respect of service-based self advocacy groups, Weafer (1993) suggested that although these groups probably achieve a high level of user independence and may have advantages in terms of ability to directly influence what happens in a particular service and deal with day-to-day issues of participants, there are questions about the independence of these groups and their representativeness of service users.
A paper by Dowse (2001) questions whether the growth of Self Advocacy for people with intellectual disability under the policy agenda of community care reform evident in the 1980s which required that the views of people with intellectual disability be taken into account ‘has become a tool to find out what people with learning disability think of services rather than to challenge the philosophy of services and systems . . .’ (citing Aspis, 1997)

Cocks and Duffy (1993) refer to Wolfensberger in identifying an inherent problem of logic in the concept of self advocacy where advocacy is defined as acting in the interests of or on behalf of another person or group. These authors 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. Cocks and Duffy also suggest that self advocacy agencies may not result in meaningful advocacy but are primarily involved in developing skills, providing the support of other people who have similar life experiences and being a source of recreation and/or a friendship network – all useful activities but not constituting advocacy.

Whittell and Ramcharan (1998a) suggest a danger that funders might seek to set the self-advocacy agenda, for example, by specifying how funds are to be utilised. Hayden (1998) also describes potential dangers for self advocacy groups, such as undue influence from funding sources, involvement in policy and program development or research that is not related to or in the best interests of the self-advocacy organisation and the personal issues of advisors such as overly controlling or caretaking behaviours.

Analysis of data from an All Wales Strategy survey of self-advocacy groups in Wales concludes that participation from the self-advocacy movement in service planning forums had been only partially successful. Difficulties are identified with practical issues such as making meetings more accessible, providing support, maintaining the independence of groups and funding. Whittell and Ramcharan (1998a) find that whilst carers were involved in local planning from an early stage of the AWS, people with learning disability were ‘conspicuous by their absence’ and that many counties had assumed that family carers would fill the role of representing people with learning disability. When people with learning disability were involved in planning groups, questions arose regarding:

- the extent to which people with learning disability contribute to such meetings (an analysis of the minutes of local planning meetings found that service users made only 3 per cent of the contributions minuted even though they comprised 24 per cent of those present)

- the level of independence that representatives from self-advocacy groups are able to maintain, particularly due to the source of self-advocacy funding (being largely from AWS)

- the extent to which self-advocacy groups have the time, support and resources to take on wider representative roles in their communities. (Whittell & Ramcharan, 1998a)
Barriers to Self Advocacy

Pennell (2001) identifies three obstacles facing self advocacy:

- lack of experience among self-advocates
- continued lack of support by the community as a whole
- many people with disability lack leadership skills.

Pennell suggest that these obstacles have not stopped the self-advocacy movement but have just redirected its emphasis with a number of projects directed at training and skills development for self advocates established. Alper, Schloss & Schloss (1996) suggest that self-advocacy training groups such as People First and Partners in Policy Making highlight the importance of self-advocacy.

Earlier research conducted by Wolfe, Ofiesh and Boone in 1996, surveyed ‘mental health/mental retardation/developmental disabilities’ agencies across 50 states shortly after the enactment of the Americans with Disabilities Act. The research finds that almost every respondent identified multiple barriers to consumer self-advocacy. The barriers included systemic barriers such as:

- 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
- 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.

In Australia, Bramley & Elkins (1988) identify a number of problems and barriers encountered by self-advocacy groups, including:

- lack of funding (e.g. resulting in non-attendance of representatives at national meetings)
- lack of public awareness of self-advocacy and self-advocacy groups
- community antipathy towards self-advocacy (e.g. having to convince parents 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.

Bramley & Elkins lament the lack of documentation on the processes, problems and achievements of Australian self-advocacy groups. In particular, these authors cite a lack of empirical studies of the intensity and duration of involvement of people in self-
advocacy groups, their acquisition of skills and progress towards independence and self-determination.

Bramley & Elkins conclude that:

The development of self-advocacy for and by intellectually disabled people is a slow, long and sometimes painful process, which needs ongoing support, tenacity, faith, and a modicum of luck. It is also evident that until very large numbers of people with intellectual disabilities can be encouraged to join and work within self-advocacy groups, the movement remains, vulnerable, and groups may collapse if key leaders or support people fail to maintain their momentum.  (p.156)

**Importance of Good Support**

Bramley & Elkins note that each self-advocacy group is unique with its own set of experiences, abilities and problems and stressed the importance of the role of advisor, particularly in the formative years of a self-advocacy group.

Whittell and Ramcharan (1998b) highlight the importance of good facilitative support ‘from an independent facilitator who is not employed by health or social services’.  (p.51) Hayden (1998) suggests that facilitators/advisors should examine their own personal issues and how these may hinder their ability to assist self-advocates. Advisors should also: point out when outside contributions and interests have the potential to move self-advocates away from their primary purpose and common welfare; support self-advocates in learning how to resolve problems and conflicts; and assist self advocates to set boundaries (such as time commitments) with professionals, advisors and other self advocates.

Bramley & Elkins point to features of the American self-advocacy movement as future possibilities for Australia, i.e.:

- an impressive national organisation producing high quality educational materials and assistance to groups
- a well-established network of groups with individual and shared goals
- valuable support from all levels of government.  (p.156)

**Effectiveness of Citizen Advocacy**

Interviewees in a UK study Rapaport et al (2006) considered that Citizen Advocacy was the most difficult type of advocacy to measure ‘because of the central importance of the quality of the partnership’ i.e. the relationship between citizen advocate and protégé.

**Key Findings from Evaluations of Citizen Advocacy Programs**

The Standards for Citizen Advocacy Program Evaluation (CAPE) were published by O’Brien and Wolfensberger in 1978. These standards were developed from an examination of programs which succeeded and programs which failed.  Page-Hanify (1992) wrote that these standards have been shown to be applicable in Australia but also notes that many programs are selective about which of the Citizen Advocacy principles they adopt and this compromises the success of these programs.
O’Brien, Elkins, Tuck and Cummins (1991) find a significant gain in the practical and social domains of adaptive behaviour for protégés participating in a Citizen Advocacy program in Melbourne. There were no significant changes in measures of the self-concept of protégés. As the study did not include a control group, the researchers recommend further investigations to control for variables such as delayed development, work and associated living experiences. The researchers also identify a low incidence of maladaptive behaviour amongst the protégés referred to the program and question whether the program coordinators and the referring agencies viewed protégés with maladaptive behaviour as being inappropriate for Citizen Advocacy. The researchers note that such a view would not be consistent with Wolfensberger’s suggestion in 1983 that advocacy programs should recruit a percentage of people with severe disability.

A small scale study of 75 advocate-protégé relationships in three Citizen Advocacy agencies in Vermont was conducted by Widrick, Hasazi and Hasazi (1990). This study finds that:

- a fairly broad cross-section of the community is involved in Citizen Advocacy, although the advocates included a disproportionate number of women, single and/or childless people and people employed less than full-time
- the majority of citizen advocates reported prior personal or professional experience with people with intellectual disability ('labelled mentally retarded')
- in terms of age, gender and levels of adaptive functioning, the protégés in the study were fairly representative of people with intellectual disability living in the community; however, given that Citizen Advocacy is intended to meet the needs of people with inadequate social supports, the proportion of protégés who were living with parents or other relatives was surprisingly high at 44 per cent
- the Citizen Advocacy relationships were found to endure over time, typically involving weekly or bi-weekly contact
- the advocate/protégé contact included a variety of community-based activities and social support functions
- advocates reported that they more frequently engaged in expressive social support, (e.g. interpersonal feedback, mutual activities and emotional support) than instrumental support functions (e.g. advice, technical assistance, and advocacy)
- the majority of advocates identified their primary role as that of friend and characterised the relationships as more like friendships than helping relationships
- both advocates and protégés reported high levels of satisfaction with their relationships and this satisfaction appeared to be independent of the level of severity of the protégé’s handicap and most advocate demographic characteristics.

Widrick et al note the limited scope of the study and question the ability to generalise the findings to programs nationally. The authors suggest that:

- Citizen Advocacy offices undertake more active recruitment of people who are less likely to volunteer as advocates, such as married men, to provide broader community representation
• more effort may need to be expended in reaching those persons who do not have family or other supports
• future research should aim to learn more from protégés themselves and focus more on the perceptions, feelings, and attitudes of people with more severe handicaps who may be unable to respond to interviews of the sort used in this study
• future research should also include advocates who are no longer involved in Citizen Advocacy.

Hadlow (1993) describes the development of a Citizen Advocacy service for people with mental health difficulties in the United Kingdom. Hadlow reports that having an advocate and being an advocate were generally both viewed positively. A few of the people who used the Citizen Advocacy support became volunteers and several of the advocates developed skills and confidence and moved on to paid employment. Hadlow finds that establishing partnerships that were equal and empowering was not always easy in a mental health context and notes the importance of not underestimating the motivation, skills and competencies required to be an effective advocate. Hadlow also recommends that the potential of Citizen Advocacy to be a disempowering experience should be recognised.

The project reported by Hadlow ultimately failed with the reasons described as follows:

In this specific instance, insecure funding was twinned with the requirement that the project be operational within 4 months of the worker being appointed. Hasty development led to uncertainty, and long-term objectives were subsumed by inadequate financing and because so many committees were involved. This was not a context which supported our efforts to ensure democratic and comprehensive user participation, both in the development of the service and in determining relations with advocates. Despite the very real achievement of this project, its existence was essentially tokenistic. (Hadlow, 1996, p.407)

Hadlow recommends that in future:
• health and social services should be committed to advocacy as a right
• this ‘commitment needs to be evident in health and social service planning and supported by budgets that are unambiguously dedicated to funding advocacy’ (p.408)
• Citizen Advocacy services should be planned within a long-term perspective with a planning and development time frame of at least four years
• service users should have a central role in defining and providing the service (ensuring that service users comprise at least 50 per cent of the management committee is one way to safeguard their influence).

Hunter and Tyne (2001) reflect on the outcomes of three Citizen Advocacy schemes established as part of hospital closures in Scotland. These authors suggest that in a hospital closure context, Citizen Advocacy schemes risk compromising essential features of Citizen Advocacy without meeting the crisis needs of residents. The difficulties identified in these schemes included:
• the advocacy project being drawn into the politics of the hospital and losing focus on the people the project had been created to serve
• the size and scope of the task facing a small under-funded independent organisation
• insecurity of powerful professionals in the hospital system
• unrealistic expectations
• resentment of advocates challenges to decisions or authority
• advocates being denied access to residents and families and to information
• excessive secrecy under the guise of confidentiality.

Hunter and Tyne conclude that the purchasers (funders) of the advocacy schemes had wanted crisis advocacy and that advocacy was increasingly expected to substitute for good models of support or assistance, adequate planning processes, effective care-management and real options for people’s lives.

Hunter and Tyne find that travel distance between advocate and partner is a significant variable in the longevity of advocacy partnerships.

**Success Factors**

Page-Hanify (1992) proposes a number of criteria for success of Citizen Advocacy programs and these largely reflect the CAPE standards. This author acknowledges that from the point of view of funders and the community, the key criterion for success will be a growing number of continuing, active relationships over time from which come many and varied positive outcomes for people with an intellectual disability. Page-Hanify suggests that if a Citizen Advocacy program can demonstrate this, then it is likely that most of the other criteria for success are also being met.

Page Hanify (1992) raises a concern that more than 50 per cent of Citizen Advocacy matches made in many Australian programs may be lost and that ‘each match lost represents one more person with a disability who has, yet again, been given the hope of a significant person in his or her life, and then been rejected’. (p.96) Martin (2003) cites an unpublished study of Citizen Advocacy matches in five US programs and the Illawarra Citizen Advocacy program in Australia (Elks) which found that the average duration of matches was 5.4 years.

The following benchmarks are suggested for growth in a Citizen Advocacy program:

• 15 to 18 matches per year for a new program (12-15 matches in a rural area) appears to be attainable for two full-time staff
• established programs could be expected to grow at a rate of 9 to 12 matches per year up to about 100 matches supported by two full-time staff, with the number of new matches slowing as the number of matches needing support increases. (Page-Hanify 1992, p.96)

Hindle (1993) proposes that the impact of a Citizen Advocacy Office depends on the availability of staff time to effectively balance the following key activities:

• protégé recruitment
• advocate recruitment
• advocate orientation
• matching
• follow-up and support
• ongoing training
• involvement of advocate associates.  (p.32)

Page-Hanify (1992) adds Board effectiveness as a second key factor in the success of Citizen Advocacy programs, for example, Board members needing a well developed understanding of Citizen Advocacy principles, Boards ensuring stable and assured funding free from conflict of interest, and participation in regular evaluation against Citizen Advocacy standards (CAPE).

Page-Hanify gives the following warning:

There is a grave risk that funding agencies might say the return on public money is not sufficient. It can be seen that Citizen Advocacy is not easy to do successfully, but much more could be done by Boards and staff to improve the quality of Citizen Advocacy programs to ensure their survival. Funding agencies should provide sufficient resources to State CA offices to enable essential support, training and evaluation to be carried out.  (p.98)

Limitations of Citizen Advocacy

In a 1983 paper, Wolf Wolfensberger, the acknowledged founder of Citizen Advocacy has expressed concerns that virtually from the first Citizen Advocacy offices established, a systematic inadequacy had been introduced into the entire Citizen Advocacy movement and the very reasons for which Citizen Advocacy had been conceptualised was often ignored by Citizen Advocacy staff. Wolfensberger writes that Citizen Advocacy was intended to be a strategy of optimising the likelihood that an impaired person would be protected if and when there was no family member that could or would do this. Wolfensberger’s main concerns as expressed in this 1983 paper are that:

• there has been avoidance of both minimally and very highly demanding relationships
• there has been virtually no orientation or recruitment towards almost purely instrumental relationships and formal relationships
• this has resulted in a low emphasis on the recruitment of formal advocates, such as adoptive parents, legal guardians, trustees, etc.
• Citizen Advocacy offices appear to have addressed themselves primarily to less impaired individuals
• people living with their families are more likely to be assigned an advocate than people in nursing homes and institutions.

Wolfensberger suggests that because Citizen Advocacy staff viewed formal relationships as non-normative, they have not pursued them. ‘As a result, even people who desperately need formal legal guardians may be matched with informal friends instead.’  (p.12)
Wolfensberger also expresses concerns that there is bias in the recruitment of volunteer citizen advocates towards those who were female, aged between 20 and 29 years, single, with college education and with some background in human services. Not that these views were expressed some 25 years ago in the context of American Citizen Advocacy offices.

In her study tour of Citizen Advocacy programs in the United States and Canada, Forrest (1986) finds that 'for no logical reason, some Citizen Advocacy offices just did not “work”.' (p.45)

Weafer (2003) identifies a number of organisational difficulties that are potentially associated with Citizen Advocacy:

- problems in recruiting sufficient numbers of suitable long-term advocates
- any interruption in the advocate:protégé relationships can have a traumatic impact on the protégé’s well being if not handled properly
- making a good match between advocate and protégé can by problematic
- the need for a coordinator with sufficient time and resources to manage the scheme
- the conflict between the relative benefits of an untrained citizen advocate and a more expert casework advocate for an individual
- the tendency for some citizen advocates to adopt a befriending rather than an advocacy role
- the lack of acceptance of volunteers by health professionals
- issues of confidentiality
- whether or not advocates should receive expenses.

Cost Effectiveness

Seymour and Peter (2004) conclude that Citizen Advocacy has been a very successful form of advocacy in Australia and although only small in size, these programs are efficient in providing stable advocacy to people over a long timeframe. For example, Seymour and Peter suggest that 60 motivated and articulate citizens would be able to provide far more advocacy over the long term than a paid worker.

A study of Illawarra Citizen Advocacy reported by the chair of its Board of Management concluded that a high-functioning Citizen Advocacy program can lead to more advocacy dollar for dollar than even the most conscientious paid advocacy. In this study, 68 citizen advocates reported spending a total of more than 650 hours per month with or on behalf of their protégés. (Note that one relationship alone accounted for 140 hours) The most commonly reported forms of advocacy action were social outings, meetings and phone calls. (Martin, 2003)

Martin suggests that instead of funding Citizen Advocacy programs to achieve a specified number of new matches per year, consideration should be given to assessing the quality and duration of matches.
Future Directions for Citizen Advocacy

Hunter and Tyne (2001) 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 so, they become less capable of delivering what citizen advocacy set out to do: long-term, freely give, independent relationships which offer the possibility of belonging in a network of community connections. (pp.555-6)

Ward (1986) 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. This is particularly so in relation to group advocacy programs which take up larger issues beyond the scope of any Citizen Advocacy office. The Citizen Advocacy office is there purely to arrange relationships and to support the advocates. It will never be able to do that properly if constantly responding to demands to take up wider issues. (Ward 1986, p.95)

Ward suggests that Citizen Advocacy should be accompanied by group advocacy programs, self advocacy groups, ombudsmen at state and federal levels, human rights commission, lawyers and specialised legal services, with the Citizen Advocate seeking assistance from these other programs and vice versa. Hadlow (1996) writes that Citizen Advocacy compliments Self Advocacy and Legal Advocacy.

Effectiveness of Individual Advocacy

Seymour and Peter describe individual advocacy in Australia and its effectiveness as follows:

Individual advocacy organisations employ advocates who seek to protect those people with disabilities experiencing abuse, neglect or discrimination. This advocacy form is particularly important when people with disabilities are confronted with urgent issues that need immediate address and so this form of advocacy excels at short term emergency intervention for vulnerable people. However, its capacity to support people over the long haul has to be balanced with those who need immediate short term (assistance). (p.12)

Individual advocacy as a model is not generally referred to in the overseas research literature. In the international context, individual advocacy would probably be considered to encompass all models where advocacy support is provided to an individual person with a disability, for example, citizen advocacy, self advocacy, individual legal advocacy.

Effectiveness of Family Advocacy

Seymour and Peter (2004) are of the opinion that family advocacy is not the best way to proceed because of the conflicts that may arise between the needs of the family and the needs of the person with a disability. Seymour and Peter suggest that this weakness in the family advocacy model would not occur as easily if the focus of the program was
clearly on the needs of people with disability. The authors note that the mission statement of Family Advocacy NSW addresses this potential conflict by stating that the organisation’s role is ‘to support people with disabilities lead meaningful lives through the development and support of advocacy by families’. (p.11)

A family advocacy model was used in an advocacy project designed to improve the quality of life for Pakistani and Bangladeshi families living in Birmingham, United Kingdom who had children with severe disability. The role of the advocates in this project was to befriend the families, link them to services, aid communication with services, link families with other families in the area in similar circumstances and model communication and advocacy skills to enable the families to develop these skills. The researchers evaluating this project identify a number of important considerations in providing advocacy for Asian families, for example:

- many of the women in these families negotiated their lives within set cultural family paradigms
- the men (fathers) did not make the most of the advocacy service and the reasons seemed to be embedded in cultural gender roles and religious codes of behaviour
- there were often tensions between individual and family needs. (Fazil, Wallace, Singh, Ali & Bywaters, 2004)

Fazil et al conclude that:

- empowerment has to operate within the social, cultural and familial context of people’s lives
- an advocacy service needs to be very family-oriented to succeed
- advocacy also needs to be community oriented
- advocates should be recruited from within the communities of the service users for whom they will be advocating
- advocates should be well trained and supervised and training should include exploration of the complex, social, cultural and gender implications of working with families and individuals
- advocacy should be set firmly in the context of local services
- each family’s ability to cope with their situation will differ and advocacy will need to be sufficiently flexible to accommodate these differences.

**Effectiveness of Systemic Advocacy**

Hutchison et al in their 2007 study of user-led and non-user-led disability organisations found that the success of user-led organisations was partly dependent on:

- the mobilisation of resources toward a particular political goal
- having a clear sense of direction
- working at the grassroots i.e. local, community level
- accessing valued resources.
Working directly at the local level enabled people to feel connected within the organisation, instil a sense of ownership, increase the opportunity for immediate action and build personal resources and skills... (Hutchison et al, 2007, p.711)

Hutchison et al concluded that user-led organisations (which in their study included People First Canada, Canadian Association of Independent Living Centres, Council of Canadians with Disabilities and the National Network on Mental Health) play an important role in increasing access of people with disability to resources such as affordable housing, education and adequate income. These four organisations were all focussed on systemic advocacy with many of their affiliates more involved with individual advocacy.

Hutchison et al found that a unique aspect of the relationship between the national organisations and their local affiliates was ‘the promotion of local projects as a tool for education and advocacy for change’. All of these national organisations used research as a strategy to influence public policy. Hutchison et al noted the important role of government in providing adequate funding to these organisations.
Methods of Evaluating Advocacy Models and Programs
Advocacy evaluation, as an emerging field of inquiry, is being driven to ensure accountability to funding organisations and also to promote organisational learning and to share stories and the lessons to be learned from them. (Whelan, 2009)

Challenges in Evaluating Advocacy Programs
Methodological challenges which have plagued this area are: 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; and the low capacity and interest in evaluation from advocacy organisations. (Whelan 2009, citing Reisman, Gienapp & Stachowiak, 2007; Guthrie, Louie, David & Foster, 2005)

Many advocacy organisations believe their work cannot be measured and some advocates are concerned about committing scarce resources to such activities. Funders of advocacy programs are interested in knowing if their investment in advocacy is making a difference and seeing evidence of results. (Whelan 2009)

Parsons (1994) describes the difficulties in measuring the ‘notoriously elusive’ outcomes of advocacy and measuring them against the basic principles of social justice and the very long time that it can take for advocacy to produce any important outcomes.

Hussein et al (2006) also acknowledge the challenges and complexities of evaluating advocacy work:

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. (p.89)

Rapaport et al (2006) discuss the lack of evidence on the effectiveness and usage of existing evaluation models for advocacy and suggest that this lack of evaluation evidence makes advocacy schemes vulnerable to scrutiny. These authors suggest two reasons why advocacy schemes have remained under-evaluated:

• advocacy programs tend to be excluded from existing systems designed to measure performance
• there are tensions regarding the most effective ways to evaluate advocacy services, i.e. Should the focus be on quantitative or qualitative measures? How should evaluations capture the relationship and enabling components of advocacy partnerships?

Rationale for Evaluation
Cocks and Duffy (1993) present a number of rationale for the evaluation of advocacy efforts:

• Advocacy efforts should be accountable for the quality and effectiveness of what they do and this accountability is to a number of stakeholders, including people with disability and where appropriate, sources of funds.
• Evaluation can maintain the focus of the advocacy and operationalise a set of standards.
• Evaluation can be concerned with different dimensions of advocacy (e.g. adhering to core principles, efficient resource management, or providing good quality outcomes for people with disability.

Stakeholders consulted by Hussein et al (2006) identified the following potential outcomes of evaluation of advocacy schemes:

• providing a catalyst for change and improvement of services
• helping to counter criticisms of advocacy not being representative
• confirming that advocacy accomplishes positive outcomes and is not a waste of time and money
• providing evidence to enable self-regulation
• helping funders to compare advocacy initiatives
• clarifying the definition of advocacy
• attracting new staff and volunteers.

Evaluation Frameworks and Models
A number of evaluation frameworks have been developed and reported in the research literature. Some of these tools and models are used repeatedly while others have been one-off approaches to the evaluation of an individual advocacy project.

The Citizen Advocacy Program Evaluation (CAPE) instrument developed by John O'Brien and Wolf Wolfensberger is probably the most well known and widely used advocacy evaluation tool, but is specifically designed for the Citizen Advocacy model.

CAPE consists of 36 ratings which are grouped into three cluster categories: adherence to Citizen Advocacy principles; Citizen Advocacy office effectiveness; and program continuity and stability. There are subgroups within these cluster categories, for example, the 20 ratings in the ‘adherence to Citizen Advocacy principles’ category are in subgroups under the headings of advocate independence, program independence, clarity of staff functions, partner characteristics, advocacy roles and positive interpretations of handicapped people. (Forrest, 1986)

CAPE is designed for use in evaluations by a team of at least three experienced raters who have previous CAPE workshop and evaluation training experience. There is a standardised format for evaluations using CAPE described by Forrest (1986) as follows:

In advance of the on-site evaluation, team members review representative agency documentation, and study or review CAPE. While on site, the team members interview individuals who represent every aspect of the CA agency operation, including all or at least the senior staff members, all or selective board members, selective partners, selective advocates, and selective related human service agency staff. The files and office documents are also studied on site. Once all of the relevant needed information has been collected, the team members retire in order to privately and individually come to a preliminary conclusion where the agency stands in relation to each of the 36 ratings. . . . Once all of the members have finished their individual rating level judgements,
then the team meets as a whole and conducts what is called “conciliation”. . . The team leader guides the rest of the team through a set routine for analysing each rating. This routine requires an exhaustive sharing of the relevant evidence, then weighing it negatively or positively, selecting the rating level which most accurately characterises the performance of the CA office and formulating recommendations. . . A team also standardly engages in an analysis of issues . . (p.37)

In the United Kingdom, where a paucity of evaluation evidence was reported, Rapaport et al (2006) found that the main measures used to monitor advocacy services were:

- reliance on reputation
- instituting an audit
- assessment performance against the funding contract
- holding regular reviews
- reading the advocacy organisation’s annual report.

The interviewee’s in Rapaport et al’s study (2006) identified the following evaluation tools:

- 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.

A 2005 paper by Rapaport, Manthorpe, Moriarty, Hussein and Collins examines several models of advocacy evaluation. A summary of the findings appears in Table 2.
## Table 2  Summary of Evaluation Models (adapted from Rapaport et al, 2005)

<table>
<thead>
<tr>
<th>Model</th>
<th>Process</th>
<th>Advantages and Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citizen Advocacy Program Evaluation (CAPE)</td>
<td>Coordinators are interviewed CAPE uses rating scale to score standards.</td>
<td>Advantages:</td>
</tr>
<tr>
<td></td>
<td>Standards include:</td>
<td>- Links principles to practice</td>
</tr>
<tr>
<td></td>
<td>- Independence of the scheme</td>
<td>- Objective measure against set of constant standards</td>
</tr>
<tr>
<td></td>
<td>- Loyalty of advocates to their partners (protégés)</td>
<td>- Develops advocacy culture</td>
</tr>
<tr>
<td></td>
<td>- Centrality of relationship between advocate and protégé</td>
<td>Disadvantages:</td>
</tr>
<tr>
<td></td>
<td>- Must not resemble a care service</td>
<td>- Only applicable to Citizen Advocacy schemes</td>
</tr>
<tr>
<td></td>
<td>Advocacy partnerships (8) and staff are interviewed by a CAIT evaluation team.</td>
<td>- Unable to measure impact of the advocacy scheme</td>
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<tr>
<td></td>
<td>CAIT investigates:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Range of clientele</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Advocacy roles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Advocate preparation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Advocate loyalty to partners</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Focuses primarily on outcomes rather than principles.</td>
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</tr>
<tr>
<td></td>
<td>Uses tables to count::</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Number of tasks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Time taken</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Different advocacy roles</td>
<td></td>
</tr>
<tr>
<td>ANNETTE (devised by Newcastle Council for Voluntary Service)</td>
<td>Adapteform of CAPE-revised was used</td>
<td>Advantages:</td>
</tr>
<tr>
<td></td>
<td>Coordinators and additional staff were interviewed</td>
<td>- Can be used in a range of advocacy schemes</td>
</tr>
<tr>
<td></td>
<td>Psychological testing of advocates using MMPI-2 and comparative measures</td>
<td>- Measures process and benefit</td>
</tr>
<tr>
<td></td>
<td>Sample of partners (protégés) were interviewed</td>
<td>- Allows for comparison between advocacy schemes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Meets contract objectives and is liked by funders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disadvantages:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Potential to overlook subtle success</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- More suited to casework advocacy than long-term Citizen Advocacy partnerships</td>
</tr>
<tr>
<td>Citizen Advocacy Lincolnshire Links (CALL) – evaluation of CALL's citizen advocacy project for young people</td>
<td>Adapted form of CAPE-revised was used</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coordinators and additional staff were interviewed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychological testing of advocates using MMPI-2 and comparative measures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sample of partners (protégés) were interviewed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Advantages:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Use of adapted CAPE-revised provided organisational context</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Used multiple methods for validity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Project team and staff involved in shaping the evaluation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Recognised importance of personality characteristics of advocates</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disadvantages:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Learning disability clientele not interviewed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Time-consuming nature of psychological intervention</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Poor response of funders</td>
</tr>
</tbody>
</table>

APPENDIX A  Review of the Research Literature 35
Table 2  Summary of Evaluation Models - Continued

<table>
<thead>
<tr>
<th>Model</th>
<th>Process</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia service self-evaluation</td>
<td>Devised questionnaire in consultation with advocacy network. Questionnaires were sent to carers and professionals in contact with the advocacy project. The questions investigated: • Awareness, understanding of and access to the service • Quality of advocacy and its effects eg impact of advocacy on the service user • Interviews (planned)</td>
<td>Advantages: • Scope of questionnaire • Obtained useful data</td>
<td>Disadvantages: • Poor response to questionnaire (30%) • Service users declined to be interviewed</td>
</tr>
<tr>
<td>RETHINK (mental health service)</td>
<td>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.</td>
<td>Advantages: • Engaged service users • Cheap and easy to implement • Meets funders’ objectives</td>
<td>Disadvantages: • May not be appropriate for people with cognitive impairment, particularly where the impairment is severe • Absence of standardisation and evaluator independence</td>
</tr>
</tbody>
</table>

Rapaport et al (2005) conclude that advocacy outcomes are difficult to measure, largely due to the range of advocacy schemes and their different aims and objectives. These researchers also recognise the importance of advocacy evaluation:

Whilst evaluation may seem to threaten the independence of advocacy schemes, overlook the success stories of long-term partnerships and favour time-limited focused advocacy, services need reliable sources of funding to survive and thrive, and they need to be publicly accountable. (p.316)

Hussein et al 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 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 Hussein et al’s 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.

In addition to a requirement for external evaluation, the Citizens Information Board which funds advocacy projects in Ireland requires half-yearly reports. The reports are to include numbers of enquiries, numbers of cases undertaken and completed, referrals and financial summaries. An annual report from each advocacy project ‘will set out the organisation’s advocacy work in more detail, describing outcomes in terms of improvements in people’s lives, as well as detailing demographic characteristics of clients, profile of clients’ needs, referrals and complaints’. (Citizens Information Board, 2007)

Bradley (1983) reports on an evaluation of ten advocacy projects providing services to people with developmental disability and mental illness in America. An initial step in the evaluation process involved evaluation staff working with key staff in the advocacy agencies to identify each agency’s four primary client-targeted goals and the two most important system reform goals. These six goals then formed the core of the evaluation for each of the ten advocacy projects.

The evaluation used four instruments to collect information related to the six identified goals:

1. Individual Client Profile – collected information about individual client characteristics, problems presented, strategies used and interim and final outcomes for the case as well as staff time spent on case-related activities in six activity areas.
2. Aggregate Client Data Collection Instrument – recorded information on all cases opened and closed by the project over a six month period.
3. Project Overview Instrument – recorded general information about project caseloads and information on system reform activities undertaken in the identified areas.
4. Staff Time and Budget Instrument – collected detailed information on project resources and costs, including income sources, staff salaries and overhead expenses and proportion of time staff spent in each activity area. (Bradley, 1983)

Evaluation staff also conducted two to three-day site visits at each advocacy agency during which time they observed advocates’ routines, talked with clients, and interviewed key informants at state and local level. (Bradley, 1983)
Another evaluation framework has been developed by Organisational Research Services who attempted to combine the common elements of the diverse frameworks into a six-part ‘menu of outcomes for advocacy and policy work, i.e.:

- shifts in social norms
- strengthened organisational capacity
- strengthened alliances
- strengthened base of support
- improved policies
- changes in impact.

The menu includes examples of outcomes, strategies and units of analysis and there is also a handbook on data collection techniques. (Whelan 2009, p.42)

The Advocacy and Empowerment Project was an American education program for people with disability and family members to teach them about abuse, neglect and financial exploitation. Three instruments were used to evaluate workshops conducted as part of this project: a workshop evaluation form; before and after training assessment; and follow-up survey. The Before and After Training Assessment was designed to measure changes in knowledge and attitudes about disability and abuse and contained 18 true and false questions about disability and maltreatment, ten attitude statements with a level of agreement scale and four statements where participants were asked to rate their level of knowledge. (Fitzsimons-Cova & Horner-Johnson, 2000)

Pederson, Chaikin, Koehler, Campbell and Arkand (1993) provide an example of a Self-Evaluation form for committee or board members and researchers to evaluate the effect of having a person with intellectual disability/developmental disability serving on the committee of board (developed by Oldendick, 1992) and a self-evaluation checklist of outcome indicators that people with these disabilities can use to evaluate their own personal skill development and impact on the operation of the committee or board.

Emerging Evaluation Models

Recently a ‘composite logic model’ has been produced by the Harvard Family Research Project which ‘represents a full range of inputs, activities, outcomes, and impacts that may be connected to an advocacy and policy change strategy from which the strategies or evaluator selects those most relevant to their work’. (Whelan 2009, p.42) Whelan goes on to explain that the model provides a ‘birds-eye point of view’ with each box/category able to be defined in more detail. Contextual factors such as changes in political, economic and social climate are also included. Whelan reports that the logic model has already been successfully used to evaluate an Australian advocacy campaign. (citing The Change Agency 2007).

Whelan (2009) discusses the utility of logic models, (otherwise known as ‘theory of change’ or ‘critical path analysis’) for advocacy programs, i.e. that organisations should have a theory of change underlying their work and articulate (perhaps in diagrammatic format similar to a flow chart), how change is achieved and what steps are required along the way. Whelan suggests that theories of change diagrams can be very useful for strategic planning purposes in advocacy organisations and also helpful for evaluators by providing intermediate outcomes that can be measured for success and by
demonstrating the strategies adopted and the assumptions that lie behind these strategies.

Whelan (2009) concludes that some of the common principles which have emerged for advocacy evaluation emphasize broadening outcome categories beyond simple legislative/policy success or failure to include things such as:

- shifts in social norms
- strengthening organisational capacity and alliances
- impact on the target group
- linking outcomes to a ‘theory of change’ explaining the logic behind certain strategic choices
- focussing on the achievement of intermediate steps required for long-term social and policy change. (pp.42-43)

Parsons (1994) offers the following advice when developing approaches to evaluating advocacy:

- don’t try to develop a model that can be applied to every type of advocacy
- don’t try to develop a way of measuring only highly tangible, visible outcomes
- don’t expect the most important outcomes to be immediately evident
- always look to involve in the evaluation process people (including people with disability) who will be able to provide you with helpful insights into the questions that you are trying to answer. (pp.187-189)

The important thing, whatever way you go about it, is to recognise evaluation as a means of keeping an eye on what you are doing. A good evaluation process is one which will tell you whether or not you are moving in the right directions. When you are, it will tell you why you are, and when you are not it will tell you why you are not.

Evaluation, like advocacy itself, is therefore really a very simple thing conceptually. But, also like advocacy, it is the doing that makes it so hard. (Parsons 1994, p.189)
Standards and Performance Indicators
Cocks and Duffy (1993) recommend that standards for advocacy organisations should address at least the following six issues and areas of operation:

1. the core principles of advocacy
2. specific principles for specific advocacy types
3. the structures which are utilised to provide advocacy
4. the actual practices of the advocacy effort
5. outcomes for the person/people with disability
6. financial and other resource management issues

Cocks and Duffy further suggest that quality standards should incorporate the principles of:

- comparability (standards make it possible to determine the extent to which an advocacy effort is achieving certain quality outcomes and the extent of further improvement or development which is needed)
- optimality (the standards reflect ideals to which advocacy should aspire rather than minimal acceptable levels)
- communicability (the standards are understood and can be clearly communicated among key stakeholders)
- universality and specificity (some standards reflect issues of quality which apply to all advocacy efforts and other standards apply to specific advocacy types or situations).

In its Advocacy Guidelines, the Citizens Information Board in Ireland (2007) describes the following principles of advocacy practice:

- empowerment of the person with a disability where possible
- respect for the person and his/her wishes
- taking account of the person’s best interests
- acting independently
- maintaining confidentiality
- acting with diligence and competence.

In respect of advocacy projects, the CIB Guidelines also recommend that:

- the advocacy project seeks to empower people with disability
- the advocacy project has a clear purpose and specific target group
- members of the target group have equal access to the service
- the service provided is independent and the potential for conflicts of interest is reduced
- advocates are trained, supported and supervised to agreed standards
• mediated rather than adversarial processes are used where possible
• confidentiality and data protection policies are developed
• projects follow best practice in terms of governance and financial transparency.

The CIB Advocacy Guidelines recommend that advocacy project reporting procedures should monitor the following areas:
• number and complexity of advocacy cases undertaken
• the effectiveness of the advocacy process
• the empowerment aspects of the service
• improvements in the life of the person with disability
• regular feedback from clients on their experience of the service
• identification of social policy issues arising from individual cases.

Barnes, Brandon and Webb (2002) recommend a large number of performance indicators for use in annual reviews of independent specialist advocacy services in the mental health sector. These performance indicators include:
• rate of referrals to the advocacy service
• diversity of service users
• reasons advocacy support is sought
• range of advocacy work done
• outcomes for service users
• number of short cases/enquiries
• number of sessions/drop-ins
• joint work with other services
• attendance at national and regional networking meetings
• systemic issues flagged
• satisfaction feedback
• number and nature of complaints about the advocacy service
• changes to policy and practice
• percentage of accredited staff
• workload per advocate
• staff turnover
• number and type of training courses attended by staff
• achievement of management objectives
• audited financial accounts.

Although directed at more generic consumer advocacy rather than disability advocacy, Field (2006) in a research paper prepared for Consumer Affairs Victoria, recommends
that key performance indicators should be developed to address three key areas (purpose, function and organisational management) as shown in Table 3.

Table 3  Key Performance Indicators Recommended for Consumer Advocacy Organisations

<table>
<thead>
<tr>
<th>Key Performance Indicators should be developed to address:</th>
<th>Example of a Key Performance Indicator for this area</th>
</tr>
</thead>
<tbody>
<tr>
<td>The purpose of the consumer advocacy organisations:</td>
<td>(For consumer advocacy on the matter of competitive markets)</td>
</tr>
<tr>
<td>• competitive markets</td>
<td>Consumer advocacy organisations should provide a clear, consistent and considered voice for the benefits of competition and to counter producer groups that seek anti-competitive arrangements harmful to consumers.</td>
</tr>
<tr>
<td>• consumer protection regulation</td>
<td></td>
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<tr>
<td>• consumer redress</td>
<td></td>
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<tr>
<td>• distributive justice</td>
<td></td>
</tr>
<tr>
<td>The function of the consumer advocacy organisations</td>
<td>(For policy advocacy)</td>
</tr>
<tr>
<td>• Individual advocacy (legal or non-legal)</td>
<td>Consumer advocacy organisations should provide advocacy to governments, regulators and others for new regulation (or removal of regulation) or some other form of policy tool to benefit consumers.</td>
</tr>
<tr>
<td>• Group advocacy</td>
<td></td>
</tr>
<tr>
<td>• Policy advocacy</td>
<td></td>
</tr>
<tr>
<td>The organisational management of the consumer advocacy organisations</td>
<td>(For optimal size)</td>
</tr>
<tr>
<td>• optimal size</td>
<td>Consumer advocacy organisations should aim to achieve an optimal size for their organisations by:</td>
</tr>
<tr>
<td>• appropriate market and consumer coverage</td>
<td>• consolidating existing resources</td>
</tr>
<tr>
<td>• flexibility and responsiveness</td>
<td>• working collaboratively</td>
</tr>
<tr>
<td>• good governance and executive management</td>
<td>• securing external resources from government, industry and philanthropic funds.</td>
</tr>
<tr>
<td>• efficiency and effectiveness</td>
<td></td>
</tr>
</tbody>
</table>

Rapaport et al (2006) identify the following difficulties experienced by advocacy networks in the United Kingdom who were trying to develop a common set of standards:

- stakeholders had differing views regarding what constituted a successful outcome
- the complexity of deciding what was being measured
- resentment from some advocacy schemes of the intrusiveness of evaluation (this was particularly so for ‘those aspiring to the purist position of total independence’ of advocacy).

The report of a previous review of the National Disability Advocacy Program (Department of Family and Community Services, 1999) raises the following problems in identifying performance indicators to measure the effectiveness and value for money of advocacy provision:

- difficulty in determining what results, either for an individual or in terms of a systemic issue, are attributable to the advocacy
- difficulty in influencing outcomes from advocacy
measuring only those results that are able to be counted will fail to recognise a large part of advocacy activity. (p.23)

The review reports contrasting views from stakeholders in respect of the feasibility of performance measurement. The review report states that: ‘Effective performance measurement would require measures of quantity and quality and should include measures of consumer satisfaction.

In a discussion paper circulated in 2000 following the NDAP review, the (then) Commonwealth Department of Family and Community Services proposed the following performance indicators:

- access to information about the NDAP and access to information about other disability specific services in the community
- level of involvement and participation of consumers in relation to advocacy issues which affect them
- provision of appropriate support mechanisms for people with severe/ profound disability
- participation and involvement of people with disability at all levels in their existing support networks
- involvement of families, carers and/or communities in supporting people with a disability
- level of consumer satisfaction with service being received.

The Queensland Strategic Reporting Framework for Advocacy (jointly developed by the Queensland State Government and the Commonwealth Department of Families, Housing and Indigenous Affairs in 2007) uses four ‘outcome’ levels to measure and report the achievement of advocacy goals and objectives. The outcome levels are:

- Results
- Immediate Results
- Services
- Systems.

Table 4 summarises the purpose, process and examples of measures that could be used to report advocacy outcomes at each of the four levels.
### Table 4 Measurement of Advocacy Outcomes in the Queensland Strategic Reporting Framework for Advocacy

<table>
<thead>
<tr>
<th>Outcome Level</th>
<th>Process</th>
<th>Examples of Measures/ Indicators</th>
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</table>
| **Results:** The ultimate outcomes or effects advocates are trying to achieve for people with a disability in line with the goals and objectives of government advocacy programs | Focuses on overall goals and objectives of advocacy. Measurement and reporting undertaken through periodic evaluations and reviews. Framework document states: ‘It is not possible to measure the contribution of individual organisations to these results, although case studies about individual organisations and clients can be used to illustrate the ways in which advocacy supports the achievement of these results.’ (p.8) | The extent to which and the ways in which advocacy contributes to:  
- Less abuse, discrimination or negligent treatment  
- More informed decision-making through better knowledge of rights and available choices  
- More equitable participation in community life  
- Better involvement of families and carers in the support system  
**For Individual Advocacy:**  
- Greater self-esteem  
- Improved and/or new skills  
- Maintenance of existing positive life circumstances  
- Maintenance of existing positive relationships  
- Improvements in information and support networks for individual  
**For Systemic Advocacy:**  
- Positive changes in legislation/protection of existing legislation  
- Positive changes in government policies  
- Changes in practices and policies of services  
- New service developments  
- Changes in community behaviour  |
| **Immediate Results:** the specific attributes directly associated with the successful provision of advocacy by funded organisations in providing advocacy. | Focuses on outcomes that directly link to the activities of funded organisations and can be clearly associated with the successful provision of advocacy. The attributes of success for immediate results will vary between organisations. Specific measures and reporting requirements will be negotiated and documented in a funding agreement between the government and the funded advocacy organisations. | Individual Advocacy:  
- Responsiveness to the needs of marginalised groups through appropriate engagement and referrals  
- Ensuring people with a disability are linked to relevant services and support networks  
Systems Advocacy:  
- Raising the profile of priority systems issues with relevant stakeholders and decision makers  
- Facilitating action to increase debate and understanding on an issue  
Citizen Advocacy:  
- Sustaining relationships between a person with a disability and a citizen who takes an interest in their wellbeing. Measures could include both quantitative data and qualitative information in the form of case studies. |
Table 4  Measurement of Advocacy Outcomes in the Queensland Strategic Reporting Framework for Advocacy (Cont.)

<table>
<thead>
<tr>
<th>Outcome Level</th>
<th>Process</th>
<th>Examples of Measures/ Indicators</th>
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</table>
| Services: the effort and activities undertaken by funded organisations in providing advocacy. | Focuses on the outputs delivered by advocacy organisations, who they work with and what they do. Service indicators will vary between organisations. Specific measures and reporting requirements at the service level will be negotiated and documented in a funding agreement between the government and the funded advocacy organisations. | Individual Advocacy:  
- The number and characteristics (disability types/ levels of vulnerability)  
- The number and type of referrals received and made  
- The number of characteristics of people with a disability who requested advocacy which could not be provided – by reason  
- Duration of advocacy  
- Amount of time/ workload response expended on advocacy work.  
Systems Advocacy:  
- The number of submissions regarding issues for people with a disability  
- The number of campaigns/ actions undertaken/ issues worked on – by field of work  
Individual and Systems Advocacy:  
- The amount of training and community education undertaken  
Citizen Advocacy:  
- The number and duration of relationships between a person with a disability and a citizen advocate. |
| Systems: the way funded organisations organise and control their work to ensure consistent practice in line with accepted standards. | Focuses on the way funded organisations organise and control their work to ensure consistent practice in line with agreed standards. The requirement to be certified as complying with the Queensland Disability Advocacy Standards will be specified in a funding agreement between government and the funded advocacy organisations. | Internal review process.  
Peer quality reviews (e.g. CAPE)  
External quality audits against the Queensland Disability Advocacy Standards:  
Initial external assessment followed by annual maintenance assessments with a full re-assessment required every three years. |

Compiled from Australian Government Department of Families, Community Services and Indigenous Affairs and the State of Queensland (Disability Services Queensland) (2007).
A Framework for Advocacy Programs in Australia

A 1998 article by Banks and Kayess suggests that adherence to principles and process and debates (often ideologically based) about which disability advocacy process (model) is superior, detract from a focus on achieving individual or systemic outcomes. These authors are concerned that the dominance of the Citizen Advocacy model in Australia at the time of their paper, has resulted in the practice of advocacy being centred around the ideology and principles espoused by Wolfensberger, failing to recognising the structural causes of disability, continuing the medical model characterisation of disability as personal or individual rather than society, and focusing on people with intellectual disability to the detriment of people with other impairments who experience disability.

This division over process, shrouded in ideological debate, seems to have been at the core of the deepest schisms in the sector. In fact, it is ultimately an issue about funding. In Australia, an inordinate amount of energy is spent trying to persuade funding bodies that one process is fundamentally better and ideologically more sound than others and, as a result, more deserving of funding. This debate has undermined the vital links between individual and systemic advocacy. Without these links, the practice of advocacy becomes disjointed and lacking in direction. (Banks & Kayess 1998, p.167)

Banks and Kayess seek to demonstrate the inability of existing advocacy models to address the fundamental issue of rights of people with disability across a complex sector. The authors feel that a more broad-based, systemic approach is needed.

The central goal of all advocacy should be the achievement of fundamental social and cultural change to eliminate disabling barriers and ensure the rights of people with impairments, particularly the right to equality of access to participation in all aspects of society. (p.162)

Banks and Kayess (1998) describe the differences between individual and systemic advocacy and argue that these differences should be recognised and valued.

Whereas individual advocacy is about advocating for an individual or group to redress specific instances of unfair treatment, systemic advocacy describes the process of arguing for a change to systems or structures that have an on-going unfair impact. Individual advocacy requires a high level of skill in communicating with individual clients to ascertain needs. Systemic advocacy requires a high level of skill in political analysis and policy development. These differences need to be recognised and valued. (p.166)

Weafer (2003) supports the need for a range of models of advocacy.

For those resourcing advocacy the important thing is that diverse forms of independent advocacy should develop and be available and known to those who need them. It is also vital that the various models are evaluated in practice to establish if they do in fact help people make informed decisions or get their needs, rights, opinions and hopes taken seriously. (Weafer, 2003, p.48)

Banks & Kayess consider that it is not possible or appropriate to use one advocacy methodology to approach all the diverse disabling barriers for all people with impairments and they argue that advocacy must adopt a diversity of models. They
propose a single framework for advocacy in Australia that fosters flexibility while remaining centred around a core theme. The framework should have a clear purpose, roles, goals and principles (principles should be about increasing access and not limiting the practice of advocacy to particular individuals). The framework should establish parameters within which activities can be defined and developed.

Banks & Kayess suggest that the key to nurturing the vital linkages between individual and systemic advocacy would be to strengthen networking and referral between advocacy groups. They also propose that highly skilled, professional advocates working in conjunction with people engaged in individual advocacy are needed if far-reaching social changes are to be achieved through the removal of disabling barriers.

Seymour and Peter (2004) cite a number of authors (Cross & Zeni 1993; Byrne 2000 and Peter 2000) who have highlighted a lack of agreement in Australia on what advocacy is and how it is done. Seymour and Peter note that Wolfensberger suggested a multi-layered framework for advocacy to address both personal and systemic concerns.

Seymour and Peter consider that Australia already has the foundation of a multi-layered approach to advocacy, i.e. there is an array of different forms of advocacy, each addressing different issues and using different advocacy models. Seymour and Peter consider that this diversity ensures that both short term issues and long term changes are considered.

Cocks and Duffy (1993) argue against the mixing of advocacy functions within organisations due to the possibility of ‘antagonistic forces developing’.

. . . an advocacy effort which includes both individual and systemic advocacy will inevitably encounter situations where the broader interest conflicts with the individual interest, in much the same way as occurs in formal human services between the broader societal or organisational purposes and the well being of the individual. . . Given the more immediate, pressing needs of individuals, it is highly likely that the more long-term systemic effort will lose priority and resources. (p.92)

These authors express similar concerns about other combinations such as a citizen advocacy organisation also taking on systemic advocacy, or a systemic legal advocacy agency also providing individual legal advocacy. Cocks and Duffy do acknowledge that advocacy efforts need to be sufficiently grounded in direct contact and involvement with people with disability but suggest that this grounding needs to occur in ways other than mixing systemic and individual advocacy.

Cocks and Duffy (1993) suggest that there are a number of potential benefits from the development of national and international advocacy networks. They cite the following potential outcomes identified by Cross in her 1992 report on advocacy in South Australia:

- developing a greater and clearer understanding of the various forms of advocacy
- learning from the approaches and strategies of different advocacy efforts
- sharing information on the foundations and structures of advocacy
- identifying common problems, issues and concerns and the priorities of these
• uniting around common and important issues to strengthen the total advocacy effort
• providing moral support to one another.

Cocks and Duffy (1993) suggest the following advocacy support mechanisms to promote high quality, effective advocacy and support the development of local, national and international advocacy efforts:

1. Research and development activities focussed on the nature of advocacy, the need for advocacy, the principles underpinning good quality advocacy and the efficacy of different advocacy types and activities.
2. Education and training for stakeholders in advocacy, including people with disability, advocates, family members, citizens and service providers.
3. Standards, quality measures and evaluation methodologies for advocacy.
4. A bank of information on advocacy and a clearinghouse function.
5. Publication and distribution of literature on advocacy.
6. Consultancy support to advocacy efforts, e.g. advice on the establishment of advocacy organisations and advising on or conducting evaluations.
7. Public events, workshops and conferences on advocacy issues and the promotion of advocacy.

Cocks and Duffy (1993) recommend that a mechanism be established within each state and territory to identify local priorities, allocate resources and ensure appropriate accountability for advocacy efforts and at the national level, there be a mechanism to address national advocacy issues and make recommendations to the appropriate Minister on the priorities and funding of advocacy.
Previous Reviews of the Government-Funded Advocacy Programs in Australia

The Commonwealth Disability Services Act (1986) provides for the funding of three types of advocacy programs:

- self advocacy
- citizen advocacy
- group advocacy.

The Disability Services Act defines these types of advocacy as follows:

**Self Advocacy Services**
Services to assist persons with disabilities to develop or maintain the personal skills and self-confidence necessary to enable them to represent their own interests in the community.

**Citizen Advocacy Services**
Services to facilitate persons in the community to assist persons with disabilities or the families of, and other persons who provide care for or assistance to, persons with disabilities, to represent their interests in the community.

**Group Advocacy Services**
Services to facilitate community organisations to represent the interests of groups of persons with disabilities. (Adapted from Section 7, Disability Services Act, 1986)

At present, six models of advocacy support are used in NDAP-funded advocacy agencies (Individual, Systemic, Self, Citizen, Family and Legal Advocacy) Please refer to section 1.1 of the main research report for a description of these models.

In 1995, the Commonwealth Department of Human Services and Health commissioned the Disability Advocacy Effectiveness Project with the aim of integrating work undertaken to date on advocacy with information obtained from nationwide consultations. The report of this project recommended that the Department adopt two broad categories of disability advocacy:

- Individual advocacy
- Systemic advocacy.

Individual advocacy was defined as:

Provision of support to individuals with a disability (and where appropriate their families or carers) who are pursuing or affected by human rights or social justice issues. (MGM Consultants 1995, p.iv)

Systemic advocacy was defined as:

Action taken to influence or produce systemic change to ensure fair treatment and social justice for people with disabilities. Changes may be pursued in
MGM Consultants recommended that these two categories should formally replace the existing categories of self advocacy, group and citizen advocacy through a review of the Disability Services Act 1986.

A further review of the NDAP was conducted from 1996 (under the Commonwealth Department of Health and Family Services) with a final report released in 1999 (through the Department of Family and Community Services). This review was managed by an interdepartmental Steering Committee and advised by a Reference Group. The review was tasked with examining the objectives, effectiveness and equity of the program and was required to advise and recommend on policies and processes for targetting the advocacy program and for ensuring the program’s cost effectiveness, measurable qualitative and quantitative outcomes for the advocacy program and a plan for the effective distribution of resources. (Department of Health and Family Services, 1997)

A Discussion Paper released as part of the review (Department of Health and Family Services, 1997) noted a number of issues that had been raised in respect of advocacy services. These included:

- 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
- lack of focus of the national advocacy program
- inability to evaluate the performance of advocacy service providers or the effectiveness of the program overall
- need for better coordination and consistency in funding arrangements between advocacy programs funded through different Commonwealth Government Departments (including those in the residential aged care program) and a similar lack of coordination between Commonwealth and State funding of advocacy services.

The discussion paper referred to the variety of approaches to advocacy that had developed which did not fit within the three categories defined in the Commonwealth Disability Services Act, 1986 (citizen, self and group advocacy). Particular confusion had arisen in the category of ‘group advocacy’ which at the time constituted 53 per cent of the services funded and consumed 62 per cent of the resources. The Discussion Paper noted that some organisations appeared to provide more than one form of advocacy.

The 1997 discussion paper suggested that the diversity of advocacy provision led to difficulties in measuring advocacy activities. The paper raised a proposal that in order to simplify the existing funding categories, two broad funding categories should be used: individual and systemic and that the structure of any future advocacy program should create a link between these two forms of advocacy so that systemic advocacy is well informed by individual advocacy.

The review’s final report published in 1999 recommended that two categories of advocacy be adopted for the NDAP: individual and systemic. The review recommended
that the primary focus should be on individual advocacy with a small proportion of systemic advocacy at the local and regional level. (Recommendations 8 and 10). A formal mechanism to represent the interests of families with members with disabilities was also recommended. (Recommendation 14, Department of Family and Community Services, 1999)

The Steering Committee proposes the major focus of the advocacy program be individual advocacy targeted to address the needs of people with disabilities in that community. The program structure should also make provision for a limited number of state-wide systemic services which would ensure that their systemic activities are based on identified high priority needs. Organisations mostly dedicated to addressing systemic issues would further develop existing networks and build new networks with national, regional and local advocacy and community organisations for the purposes of developing a strong and coordinated approach to systemic advocacy. (Department of Family and Community Services, 1999, p.33)

**State Government Reviews and Frameworks**

In late 2005, the New South Wales Department of Ageing Disability and Home Care (DADHC) invited comment on an Issues Paper as part of its development of a new strategic direction for disability advocacy and information services and consumer peak bodies. The more than 70 submissions received supported the following proposals:

- adopting the principle of individual advocacy and strengthening pathways to effective self-advocacy and informal advocacy
- recognising and accommodating the complex needs of people with disability who are vulnerable and unable to self-advocate
- providing specialised self-advocacy training for people with disability and their families (although one quarter of the submissions argued that self-advocacy has limited benefits and may not be effective for all people or in all situations
- supplementing generalist advocacy services with specialist services, including specialist advocacy by disability type
- improving access to appropriate advocacy services for Indigenous people with disability and people with a disability from culturally and linguistically diverse backgrounds
- increasing cultural competence training for staff of advocacy services
- fostering collaboration amongst service providers
- increasing promotion and awareness of the rights of people with disability and the services available to them
- recognising the key relationship between the dissemination of information and the provision of advocacy

There was reportedly unanimous agreement in the submissions that advocacy models be flexible and responsive to the needs, competencies and the situation of individual clients, their families and carers and a number of submissions argued for a combination of advocacy models.
Concerns were raised about the proposed use of volunteers, including the costs associated with screening, training, supervision and turnover of volunteers and the issues of accountability and liability.

There was strong support for DADHC’s proposed Service Delivery Framework which defined three service types: individual advocacy service; specialist information service; and consumer peak bodies. Some submissions supported a broader role for peak bodies, including a sector leadership role in relation to systemic issues. The establishment of a performance monitoring framework was also supported. (NSW DADHC, 2007)


The Strategic Reporting Framework documents the policy goal of advocacy and several objectives and principles (which centre around the rights of people with a disability). The Framework classifies disability advocacy service into two broad categories: Individual Advocacy and Systems Advocacy. The definition of Individual Advocacy in the Framework document includes examples of activities to support self advocacy and working with groups is included in the definition of Systems Advocacy. The document states that a range of approaches is used within the two categories, including citizen advocacy and parent advocacy.
Conclusions

The research literature is inconclusive in respect to the comparative effectiveness of the models of advocacy currently funded under the National Disability Advocacy Program, although Individual Advocacy is considered to be particularly effective for short term and urgent intervention.

The research literature does indicate:

- the need for a range of forms and types of advocacy for people with disabilities
- the need for specific resources dedicated to Systemic Advocacy (quarantined from the resource demands of Individual Advocacy)
- the potential advantages of linkages between advocacy agencies and a coordinated, collaborative approach to prioritising and addressing systemic issues
- the importance in advocacy organisations of focussed policy aims, better resource bases and skilled leadership
- the current lack of evaluation of advocacy programs but the emerging need for and potential benefits of effective evaluation
- the difficulties in identifying and applying performance indicators and measures to evaluate the effectiveness and outcomes of disability advocacy.

The findings from the literature review are consistent with the recommendations of previous reviews of the NDAP, i.e. to have two broad streams of funded advocacy: individual and systemic. The Individual Advocacy stream should incorporate a flexible range of advocacy models, including Individual Advocacy by paid advocates for people who are extremely disempowered and vulnerable, self advocacy, individual legal advocacy and possibly, citizen advocacy.

The literature also supports the provision of advocacy assistance for families and carers of people with disability.
Primary References


Citizens Information Board 2007, Advocacy Guidelines: Guiding Principles and Operating Procedures for the Delivery of Advocacy Services through Community and
Voluntary Organisations, Dublin.


Department of Families, Community Services and Indigenous Affairs 2008, *National Disability Advocacy Program Consultation Work Sheets*


Disability and Human Development, College of Health and Human Development Sciences, University of Illinois at Chicago.


MGM Consultants in Human Services 1995, *Advancing Advocacy: Disability Advocacy Effectiveness Project*, Department of Human Services and Health, Commonwealth of
Australia, Canberra.


New South Wales Department of Ageing, Disability and Home Care 2007, *Issues Paper – Future directions for disability advocacy and specialist information services and consumer peak bodies: Summary of outcomes from the consultation process*, Sydney


Appendix B
Questions for Interviews with Representatives of Peak Disability Bodies
Appendix B
Questions for Telephone Interviews with Peak bodies

About Your Organisation

1. Which group or population does your organisation represent?
2. What advocacy support needs does this group or population have?
   e.g. In what situations does this group need advocacy?
   What models of advocacy are needed?
   Do advocacy agencies need specialist skills to provide support for this group?
3. What involvement or interaction does your organisation and its members have with
   advocacy agencies funded under the National Disability Advocacy Program?

Achieving Positive Outcomes

From the experience of your organisation and its members:

4. What positive outcomes have been achieved for people with disability as a result of
   advocacy support provided by NDAP-funded agencies?
5. Are there circumstances where a particular model of advocacy has achieved positive
   outcomes? (i.e. individual, systemic, self, citizen, family or legal advocacy)
6. Are there any barriers or issues that prevent advocacy agencies from achieving
   positive outcomes for people with disability?
7. What do you consider would be the most important outcomes for people with
   disability as a result of receiving advocacy support?
8. What are the barriers to achieving these positive outcomes?
9. Are any of these barriers or issues associated with a particular model(s) of
   advocacy?
10. What strategies could be used to overcome these barriers?

Contributing to Systemic Change

11. In what ways can advocacy contribute to systemic change (e.g. changing
    organisational cultures, improving disability service practices and procedures,
    legislative change)?
12. Are there any practical examples you can describe where advocacy has resulted in
    systemic change?
13. Are there any models of advocacy that are particularly effective in contributing to
    systemic change? (i.e. individual, systemic, self, citizen, family or legal advocacy)
    If yes, which models and why are they effective?
14. Does your organisation feed any issues into systemic advocacy agencies? If yes,
    what sort of issues? To which advocacy agencies? What outcomes are achieved
    from this?
15. How could the models of advocacy and the way these models work together be strengthened to promote positive systemic change?

Use of Advocacy Resources
16. Are there any ways in which the use of advocacy resources could be improved? (i.e. could resources be used more effectively or more efficiently?)

Collaboration between Models of Advocacy
17. Can you describe any examples of advocacy from NDAP-funded agencies contributing to public policy? (e.g. advocacy informing government decision-making, contributing to improvements in government policies and programs.)
18. Is there a particular combination of models of advocacy that achieves more positive outcomes than either model used alone?
19. Could collaboration between models of advocacy be improved and if so, how could this be done?

Effect of Advocacy on Public Policy
20. How effective are the models of advocacy in feeding into public policy?
21. Have any of the models of advocacy (i.e. individual, systemic, self, citizen, family or legal) been particularly effective in feeding into public policy? In what way(s)?

Meeting Present and Future Needs
22. Are the current models of advocacy used in Australia appropriate for meeting the present and future needs of people with disability?
23. Are any modifications or development of the models of advocacy required to meet current and future needs?
24. What should a future model or models of advocacy look like?

Indicators of Success
25. What indicators or measures do you think the government funder of advocacy programs should use to evaluate the appropriateness, effectiveness and efficiency of a national program of advocacy support for people with disability?
26. What indicators or measures would be the most important in evaluating the overall success of the national program?
Appendix C
Questions for Interviews with FaHCSIA State/Territory Office Staff
Appendix C
Questions for Interviews with FaHCSIA State/Territory Office Staff

About Your Role(s) in the National Disability Advocacy Program

1. Briefly tell us about your role(s) and involvement in the National Disability Advocacy Program.

Effectiveness of the Models of Advocacy

2. How effective in your opinion is each of the models of advocacy in respect of assisting people with disability?
   - Individual Advocacy?
   - Self Advocacy?
   - Citizen Advocacy?
   - Family Advocacy?
   - Systemic Advocacy?
   - Legal Advocacy?

How much of this effectiveness is due to the model and how much is due to the qualities of the manager of the advocacy agency or other personnel?

Achieving Positive Outcomes

2a. What positive outcomes have you observed for people with disability receiving advocacy support?
2b. What do you see as the desired positive outcomes for people with disability receiving support from NDAP funded agencies?
2c. Is there a particular model or models of advocacy that is more likely to achieve positive outcomes for people with disability? If yes, is there evidence to demonstrate this?

Contributing to Systemic Change

2d. Are there practical examples you have seen where advocacy has contributed to systemic change (e.g. changing organisational cultures, improving disability service practices and procedures, changes to public policy, legislative change)?
2e. Are there any models of advocacy that are particularly effective in contributing to systemic change? If yes, which models and why are they effective?
2f. How could the linkages between advocacy and systemic change be improved?

Collaboration between Models of Advocacy

2g. What are the advantages of collaboration between models of advocacy? Do you have examples of where this currently works well?

2h. How could collaboration between models of advocacy be improved?

Use of Advocacy Resources

3. Do the models of advocacy differ in how they manage resources and governance arrangements?

3a. Are any of the models of advocacy more effective and efficient in your opinion? Why?

3b. What are some of the challenges facing advocacy models in terms of managing resources and governance arrangements?

3c. Have you come across examples of good/best practice around resource management that are more applicable to some advocacy models?

3d. Are there any ways in which the use of advocacy resources could be improved? (i.e. could resources be used more effectively or more efficiently?)

Meeting Present and Future Needs

4. Are there any changes you would suggest to the models of advocacy in order to better meet the present and future needs of people with disability?

Indicators of Success

5. What indicators or measures do you think FaHCSIA should use to evaluate the appropriateness, effectiveness and efficiency of a national program of advocacy support for people with disability?
Appendix D
Discussion Group Questions
Appendix D

Discussion Group Questions

About Your Organisations

1. By way of introduction, briefly tell us about each of your agencies, the profile of people you assist and the models of advocacy that you use?

Achieving Positive Outcomes

2. What do you consider would be the most important outcomes for people with disability receiving advocacy support?

3. Without identifying any individuals, can you describe any practical situations or scenarios where a specific model of advocacy has been particularly successful in achieving positive outcomes?

4. Are there circumstances where each of the models of advocacy is most likely to achieve a positive outcome for the consumer?
   - individual advocacy?
   - systemic advocacy?
   - self advocacy?
   - citizen advocacy?
   - family advocacy?
   - legal advocacy?

5. Are there circumstances where a particular model or models of advocacy is unlikely to achieve a positive outcome?

6. What are the barriers to achieving positive outcomes for people with disability receiving advocacy support?

7. How could these barriers be overcome?
Contributing to Systemic Change

8. Are there any practical examples you can describe where advocacy has resulted in systemic change? (e.g. changing organisational cultures, improving disability service practices and procedures, legislative change)

In these examples, what model(s) of advocacy was/were used?

What other strategies or events assisted in achieving systemic change?

9. Are there any models of advocacy that are particularly effective in contributing to systemic change? If yes, which models and why are they effective?

10. Do other advocacy models feed issues into systemic advocacy agencies?

Collaboration between Models of Advocacy

11. Are there other practical ways in which the different models of advocacy interact, link or complement each other to achieve positive outcomes for people with disability?

12. Is there a particular combination of models of advocacy that achieves more positive outcomes than either model used alone?

13. Could collaboration between models of advocacy be improved and if so, how could this be done?

Effect of Advocacy on Public Policy

14. How effective are the models of advocacy in feeding into public policy?

15. Do you have any examples of advocacy agencies contributing to public policy consultations, research, evaluation, planning or decision making?

16. How could the linkages between advocacy and public policy be improved?

Use of Advocacy Resources

17. Are there any ways in which the use of advocacy resources could be improved? (i.e. could resources be used more effectively or more efficiently?)
18. Do any of the models of advocacy demonstrate an advantage in terms of the duration and/or intensity of support required to achieve a positive outcome for consumers?

Meeting Present and Future Needs

19. Are the current models of advocacy used in Australia appropriate for meeting the present and future needs of people with disability?

20. Are any modifications or development of the models of advocacy required to meet current and future needs?

21. What should a future model or models of advocacy look like?

Indicators of Success

22. What indicators or measures do you think the government funder of advocacy programs should use to evaluate the appropriateness, effectiveness and efficiency of a national program of advocacy support for people with disability?

23. What indicators or measures would be the most important in evaluating the overall success of the national program?

24. Any other issues or suggestions?
Appendix E
Submission Proforma for NDAP-Funded Advocacy Agencies
Appendix E
Proforma for Submissions by NDAP-Funded Advocacy Agencies

This proforma is provided for advocacy agencies funded under the National Disability Advocacy Program. The proforma is designed to guide respondents and to enable the best use to be made of the information you provide in answering the research questions.

About Your Organisation
This information will help us to describe the profile of advocacy agencies that provide submissions for this research project and identify key issues that may be linked to particular models of advocacy or sizes or locations of advocacy agencies.

In which state or territory is your agency located?

Does your agency provide advocacy support for a specific group or population (e.g. people with a particular type of disability)? If yes, which group or population?

Which model or models of advocacy does your agency use?

Is there a predominant advocacy model used by your agency? (i.e. the model of advocacy that your agency uses the most)

Approximately how many people receive advocacy support from your agency each year?
Your Responses to the Research Questions

These research questions provide a guide for your input. Please describe practical examples where possible.

Achieving Positive Outcomes

Are there circumstances where a particular model of advocacy is most likely to achieve a positive outcome for the consumer?

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<th>Circumstances where this model is most likely to achieve a positive outcome</th>
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Are there circumstances where a particular model of advocacy is unlikely to achieve a positive outcome?

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What strategies could be used to overcome the barriers to achieving positive outcomes for consumers?

<table>
<thead>
<tr>
<th>Model of Advocacy</th>
<th>Barriers to achieving positive outcomes</th>
<th>Strategies to overcome these barriers</th>
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<tbody>
<tr>
<td>Individual Advocacy</td>
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<td>Systemic Advocacy</td>
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<td>Legal Advocacy</td>
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<tr>
<td>Barriers common to all models of advocacy</td>
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</table>
How effective is each model of advocacy in contributing to systemic change?

<table>
<thead>
<tr>
<th>Model of Advocacy</th>
<th>How effective is this model in contributing to systemic change?</th>
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<tbody>
<tr>
<td>Individual Advocacy</td>
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<td>Legal Advocacy</td>
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Please continue here if you need more space for your comments
Use of Advocacy Resources
Do any of the models of advocacy demonstrate an advantage in terms of the duration and/or intensity of support required to achieve a positive outcome for consumers?

Are there any ways in which the use of advocacy resources could be improved?

Collaboration between Models of Advocacy
Are there practical ways in which the different models of advocacy interact, link or complement each other to achieve positive outcomes for people with disability?

Is there a particular combination of models of advocacy that achieves more positive outcomes than either model used alone?
Could collaboration between models of advocacy be improved and if so, how could this be done?

**Effect of Advocacy on Public Policy**

How effective are the models of advocacy in feeding into public policy?

<table>
<thead>
<tr>
<th>Model of Advocacy</th>
<th>How effective is this model in feeding into public policy and why?</th>
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</thead>
<tbody>
<tr>
<td>Individual Advocacy</td>
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<td>Systemic Advocacy</td>
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<td>Family Advocacy</td>
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<td>Legal Advocacy</td>
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</table>
How could the linkages between advocacy and public policy be improved?

Meeting Present and Future Needs
Are the current models of advocacy appropriate for meeting the present and future needs of Australians with disability?

Are any modifications or development of the models of advocacy required to meet current and future needs?
Thank you for providing a written submission to this research project. Please send your submission by post to:

Jenny Pearson & Associates Pty Ltd
*Reply Paid address provided*

You will not need a postage stamp if you use this address.

If you have prepared your submission on computer, you can send it by email to Jenny Pearson & Associates Pty Ltd at the following address:

*Email address provided*
Appendix F
Submission Proforma for Disability Peak Bodies
Appendix F

Proforma for Submissions by Disability Peak Bodies

This proforma is provided for peak bodies in the disability sector. These organisations include those representing people with disability, the parents, families and carers of people with disability and disability service providers. The proforma is designed to guide those who wish to have input to this research project. The proforma will also assist the researchers to make the best use of the information you provide in answering the research questions.

About the National Disability Advocacy Program and the Six Models of Advocacy

The National Disability Advocacy Program (NDAP) assists people with disability to overcome barriers (for example, physical access, discriminatory attitudes, abuse or neglect) that impact on their daily life and their ability to participate in the community. Currently over 60 disability advocacy agencies are funded through the NDAP to assist up to 24,000 people with disability.

Six models of advocacy support are used in NDAP funded advocacy agencies. A general description for each of these advocacy models is presented below.

<table>
<thead>
<tr>
<th>Model of Advocacy</th>
<th>General Description</th>
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<tbody>
<tr>
<td>Individual Advocacy</td>
<td>Individual advocacy seeks to uphold the rights and interests of people with all types of disabilities on a one-to-one basis by addressing instances of discrimination, abuse and neglect. Individual advocates work with people with disability on a short-term and issue-specific basis. Formal individual advocacy is undertaken by a paid advocate employed by an advocacy agency. Informal individual advocacy is undertaken on a voluntary basis by a family member or a friend.</td>
</tr>
<tr>
<td>Systemic Advocacy</td>
<td>Systemic advocacy seeks to influence or secure positive long term changes that remove discriminatory barriers to ensure the rights and interests of groups of people with disability are upheld. Systemic advocates and policy officers employed by advocacy agencies and peak bodies undertake this advocacy.</td>
</tr>
<tr>
<td>Self-Advocacy</td>
<td>Self advocacy supports people with disability (predominantly people with an intellectual disability) to advocate on their own behalf or on a one-to-one or group basis. The advocate is paid by the advocacy agency to support people with disability to advocate on their own behalf.</td>
</tr>
</tbody>
</table>

2 These six models of advocacy have been set out in the ‘National Disability Advocacy Program (NDAP) Quality Assurance Consultations Report’. This report is available on the FaHCSIA website.
### Citizen Advocacy

Citizen advocacy seeks to support people with an intellectual disability by matching them with volunteer advocates on a one-to-one basis. Citizen advocates are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest.

Citizen advocates are supported by a paid coordinator who manages the citizen advocacy office. Some of the matches made may last for life.

### Family Advocacy

Family advocacy works with parents and family members to enable them to act as advocates on behalf of a family member with a disability. Family advocates work with parents and family members on a short-term and issue-specific basis. Family advocates work within the fundamental principle that the rights and interests of the person with disability are upheld at all times.

### Legal Advocacy

Legal advocacy seeks to defend the rights and interests of people with disability on a one-to-one basis through the Australian legal system.

Legal advocacy is undertaken by a lawyer or individual with appropriate legal knowledge.

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Around 90 per cent of NDAP-funded agencies use a combination of two or more of the six advocacy models. The most commonly used advocacy model is individual advocacy with 82 per cent of NDAP funded agencies reporting some use of individual advocacy.

This research project is investigating issues such as:

- how the different advocacy models can best achieve positive outcomes for people with a disability
- what strategies can be used to overcome any barriers to achieving positive outcomes
- how advocacy models contribute to systemic change
- how the advocacy models feed into public policy
- whether the current models of advocacy are appropriate for meeting current and future needs and how the models could be improved or developed
- collaboration between models of advocacy i.e. how different models of advocacy can work in combination or complement each other to provide a more whole of life response to the issues that people with disability encounter.

Topics and questions for your submission are presented on the following pages.
About Your Organisation
This information will help us to describe the profile of organisations that provide submissions for this research project and to identify key issues for particular groups.

Who does your organisation represent?

Does your organisation have national coverage or is the organisation based in a particular state or territory?

What involvement or interaction does your organisation and its members have with advocacy agencies funded under the National Disability Advocacy Program?

Achieving Positive Outcomes
From the experience of your organisation and its members:

What positive outcomes have been achieved for people with disability as a result of advocacy support provided by NDAP-funded agencies?
Are there circumstances where a particular model of advocacy has achieved positive outcomes?

<table>
<thead>
<tr>
<th>Model of Advocacy</th>
<th>Circumstances where this model has achieved positive outcomes</th>
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<tbody>
<tr>
<td>Individual Advocacy</td>
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Please continue here if you need more space for your comments

Are there any barriers or issues that prevent advocacy agencies from achieving positive outcomes for people with disability?
Are any of these barriers or issues associated with a particular model(s) of advocacy?

What strategies could be used to overcome these barriers or issues?

Advocacy and Systemic Change
Can you describe any examples of advocacy contributing to systemic change? (e.g. changing organisational cultures, improving disability service practices and procedures)

Have any of the models of advocacy (i.e. individual, systemic, self, citizen, family or legal) been particularly effective in contributing to systemic change? In what way(s)?
How could the models of advocacy and the way these models work together be strengthened to promote positive systemic change?

Use of Advocacy Resources
Do any of the models of advocacy demonstrate an advantage in terms of the duration and/or intensity of support required to achieve a positive outcome for consumers?

Are there any ways in which the use of advocacy resources could be improved?
Collaboration between Models of Advocacy

Are there practical ways in which the different models of advocacy interact, link or complement each other to achieve positive outcomes for people with disability?

Is there a particular combination of models of advocacy that achieves more positive outcomes than either model used alone?

Could collaboration between models of advocacy be improved and if so, how could this be done?
Effect of Advocacy on Public Policy

Can you describe any examples of advocacy from NDAP-funded agencies contributing to public policy? (e.g. advocacy informing government decision-making, contributing to improvements in government policies and programs.)

Have any of the models of advocacy (i.e. individual, systemic, self, citizen, family or legal) been particularly effective in feeding into public policy? In what way(s)?

Meeting Present and Future Needs

Are the current models of advocacy appropriate for meeting the present and future needs of Australians with disability?

Are any modifications or development of the models of advocacy required to meet current and future needs?
What should a future model or models of advocacy look like?

Do you have any other comments or suggestions regarding the models of advocacy funded under the National Disability Advocacy Program?

Thank you for providing a written submission to this research project. Please send your submission by post to:

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