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

Final Report

Submitted to
Department of Families, Housing, Community Services and Indigenous Affairs

14 September 2009
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Acknowledgements

The research team for this project comprised Jenny Pearson and Susan Hill.

We wish to thank the individuals and organisations who participated in consultations for this research project and those that provided written submissions.

The assistance provided by FaHCSIA staff in Canberra and the state offices where discussion groups were held is also appreciated.

We also thank Karen Hill and Gabriele Monis from the Disability Collection of the DFC Library and Information Service in South Australia for their helpful assistance with the literature search.

Disclaimer

A range of stakeholder comments and opinions are documented in this report. These views are not necessarily those of the consultant, Jenny Pearson & Associates Pty Ltd or the Department of Families, Housing, Community Services and Indigenous Affairs.

Stakeholder comments have been de-identified and comments are not attributed to individuals or organisations.
Executive Summary

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 lives and their ability to participate in the community. The Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) currently funds over 60 advocacy agencies around Australia through the NDAP.

Six models of advocacy are approved for use in the NDAP and funding agreements with advocacy agencies specify the model(s) of advocacy each agency will use and in what proportion. The six models of advocacy are:

- Individual Advocacy
- Systemic Advocacy
- Self Advocacy
- Citizen Advocacy
- Family Advocacy
- Legal Advocacy.

This is the final report of a research project commissioned by FaHCSIA and undertaken by Jenny Pearson & Associates Pty Ltd from late April to June 2009. The purpose of this research was to examine the appropriateness, effectiveness and efficiency of the six models of advocacy and to identify key performance indicators that could be used to measure the success of the different advocacy models now and in the future. The research also explored the interactions and linkages between the different models of advocacy, how these feed into systemic advocacy at the state/territory and national levels and how systemic advocacy influences public policy.

The project was asked to investigate the following research questions:

Q1: How effective are the six advocacy models in achieving the aims of the program?

The research shall consider:
   a) the circumstances where each model achieves a positive outcome for the consumer;
   b) the circumstances where each model doesn’t achieve a positive outcome for the consumer;
   c) barriers to the models achieving positive outcomes;
   d) strategies to overcome the barriers; and
   e) how effectively each model contributes to systemic change.

Q2: How appropriate are the six advocacy models?

The research shall consider:
   a) whether the models are relevant to the present and future needs of Australians with disability; and
   b) any modifications that need to be made to the models to meet current and future needs.
Q.3: How efficient are the advocacy models of support?  
The research shall:  
a) consider the cost of each model and its benefits to the population target group;  
b) consider the duration and intensity of support required under each model to achieve positive outcomes and outputs for people with disability and public policy; and  
c) critically review each model and advise of the most efficient model(s).

Q4: To what extent do the different models collaborate and feed into public policy?  
In considering this, the research shall have regard to:  
a) the effectiveness of the different models in feeding into public policy;  
b) the extent and effectiveness of the models in collaborating and complementing each other in practice; and  
c) the extent to which the specialist services share their knowledge to support generic services.

The research methodology included:  
- a review of Australian and international research literature  
- discussion groups with NDAP-funded advocacy agencies  
- written submissions from NDAP-funded advocacy agencies and peak disability organisations  
- interviews with stakeholders including advocacy agencies, FaHCSIA staff and disability peak bodies.

The key findings from the review of the research literature and the research consultations are summarised below.

**Key Findings from Review of the Research Literature**

The research literature is inconclusive in respect to the relative effectiveness of each 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 disability  
- 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 research literature also supports many of the issues and suggestions raised by stakeholders in the consultations for this project.

Effectiveness of the Six Models of Advocacy

Individual Advocacy
• Individual Advocacy is the most commonly used model of advocacy in the NDAP.
• In practice, Individual Advocacy often incorporates a flexible range of approaches and may use or refer to Self Advocacy, Family Advocacy, Legal Advocacy and sometimes Citizen Advocacy as required by consumers from time to time.
• Individual Advocacy appears to be the most effective model for providing short-term advocacy assistance to large numbers of consumers on a wide range of issues in both metropolitan and rural areas.
• Specialist Individual Advocacy may be required when providing advocacy assistance to people from culturally and linguistically diverse backgrounds (CALD) or Aboriginal and Torres Strait Islander (ATSI) communities or people with specific types of disability, for example, psychiatric disability and sensory disabilities. For these groups, the advocate may need detailed knowledge of specific legislation, an understanding of specialist service systems and procedures, non-English language skills, alternative communication skills and/or cultural knowledge.

Systemic Advocacy
• Systemic Advocacy when appropriately resourced and managed can achieve significant outcomes for the wider population of people with disability.
• In order to be most effective, Systemic Advocacy needs to have dedicated resources and good linkages with Individual Advocacy to enable a flow through of information about the issues affecting people with disability.
• There is strong support from stakeholders for continued funding of Individual Advocacy and Systemic Advocacy.
• The main issue when these two models are both provided by an advocacy agency is the lack of resources for Systemic Advocacy and the resultant impact on Systemic Advocacy when Individual Advocacy needs have to take precedence.
Citizen Advocacy

- Proponents of the Citizen Advocacy model have put forward many arguments in favour of this model, including:
  - assertions that this model is more cost-effective because the citizen advocates are volunteers
  - Citizen Advocacy provides long-term support and may prevent crisis situations and advocacy needs from arising
  - Citizen Advocacy programs may seek out people with complex needs at the margins of society who would not present at or contact an advocacy agency on their own initiative.

- Consultations have also identified concerns about the Citizen Advocacy model. These concerns include:
  - poor cost-effectiveness of the model, i.e. paid staff support a limited number of citizen advocate/protégé matches over an extended period of time (usually many years)
  - the model is focussed on long-term support, involves a waiting period while a citizen advocate match is found and is not designed for short-term or urgent advice or assistance
  - the low and diminishing numbers of people willing to become citizen advocates limits the number of people with disability who can be supported through this model
  - the non-professional nature of the relationship between citizen advocate and protégé may have implications for standards of practice
  - volunteer advocates may not have the skills to deal with complex matters
  - there may be a tendency for the protégé to develop dependence on one person (i.e. his/her citizen advocate) for advocacy and support needs, rather than developing a network of supportive relationships
  - there is potential for a significant negative impact on the protégé if his/her citizen advocate can no longer continue in this role
  - the advocate/protégé relationship is considered by some to be more of a social relationship or mentoring role than advocacy
  - strict adherence to the Citizen Advocacy model and principles may restrict an agency’s ability to respond to individual needs or to collaborate with other advocacy models.

- Although some of these concerns may be countered by Citizen Advocacy proponents, there remains a significant lack of confidence in this model across a range of stakeholders. Recent closures of Citizen Advocacy programs in Australia and the introduction of Individual Advocacy to others also indicate difficulties in sustaining Citizen Advocacy as a stand-alone model in some regions.
Legal Advocacy

- Significant consumer outcomes have been achieved through Legal Advocacy at individual and systemic levels.
- The Legal Advocacy required to reach these outcomes may be time consuming and expensive.
- There are conflicting views about the need for Legal Advocacy to be funded under the NDAP:
  - Some argue that legal advocacy should be accessed through mainstream services such as legal aid programs.
  - Others say that mainstream legal services do not adequately understand and respond to the needs of people with disability.
  - Advocates report difficulties in accessing mainstream legal services and even disability discrimination legal services.
  - There is a strong argument that many people with disability (particularly intellectual and psychiatric disabilities) require advocacy support in their dealings with the justice system and in other legal matters such as tribunal hearings.
  - There is a lack of clarity about whether Legal Advocacy involves only specialist advice provided by a qualified legal practitioner or if this model encompasses support and referral by a general disability advocate in relation to legal matters. In practice, both of these approaches are evident.
- Overall, it appears that there is a continuing need for specialist Legal Advocacy for people with disability at both individual and systemic levels.

Self Advocacy

- There is strong support for Self Advocacy from some stakeholders but the models of Self Advocacy that they propose vary.
- Other stakeholders consider that Self Advocacy has limitations in terms of appropriateness for people with more severe intellectual or other cognitive disabilities. Examples were given of negative consequences experienced when attempting Self Advocacy in some individual situations.
- Some agencies providing Individual Advocacy describe a progression that may occur from Individual Advocacy to Self Advocacy over time as the person with a disability develops skills and knowledge and some agencies say that they actively encourage this development.
- There is some support for providing Self Advocacy in combination with Individual Advocacy.
- Other interpretations of Self Advocacy use a more structured group approach such as ‘People First’.
- Self Advocacy may be an effective and appropriate pathway for some people with disability as an individual process or in a group model. In many situations, Self Advocacy may need to occur under an umbrella of Individual Advocacy.
support to ensure that any negative consequences of attempting unsupported Self Advocacy are avoided.

**Family Advocacy**

- Some advocacy agencies indicate strong support for Family Advocacy while others rarely or never use this model.
- The main concern raised about Family Advocacy is the potential conflict between the interests of family members and the wishes of the person with disability and how advocacy agencies manage this potential conflict.
- Agencies providing advocacy support for people with disability from ethnic communities have described the importance of working closely with families even when providing Individual Advocacy.
- Family Advocacy is an important model for parents of young children with disability and may also be required where adults with disability have close family links and/or cultural ties. This model needs to be practised with the underlying principle that the rights and interests of the child/person with disability are paramount and that Family Advocacy is about supporting family members to advocate for those rights. Separate involvement of carer/parent advocacy may be needed if there is conflict between the rights or wishes of parents or other family members and the person with disability.

**Barriers to Positive Outcomes**

- Advocacy agencies have identified a range of barriers to effective advocacy. These mainly involve:
  - a lack of resources in the advocacy sector and the wider human service system, particularly in areas such as accommodation, transport and education
  - lack of awareness and negative attitudes to disability and advocacy
  - resistance to advocacy involvement from service providers
  - prescribed models of advocacy limiting flexibility in advocacy agencies’ responses to consumer needs
  - inconsistencies between state/territory and Commonwealth government-funded advocacy programs
  - multiple accountability and reporting requirements
  - difficulties recruiting and retaining suitable staff
  - insufficient training and professional development opportunities
  - lack of knowledge of other advocacy agencies for referral, information sharing and collaboration purposes
  - legislative barriers, legal system barriers and inadequate complaints processes
  - ineffective implementation of government and service provider policies relating to people with disability
• cultural barriers
• service gaps and distance in regional and rural areas.

**Contribution to Systemic Change**

- Stakeholders generally agree that Systemic Advocacy is the model which most contributes to systemic change, although other models can feed issues into Systemic Advocacy or result in systemic changes in their own right, e.g. Legal Advocacy.
- Some examples have been described where advocacy action on behalf of an individual has resulted in broader systemic change.
- The systemic changes described by advocacy agencies include changes to service provider policy and procedures, local government initiatives such as access modifications to local buildings, changes to departmental policies at state government level, and introduction or revision of legislation.
- In many of the systemic change examples cited by stakeholders, the change has taken a long period of time to achieve (often several years) and direct cause:effect relationships between the advocacy and systemic change are often difficult to identify due to other factors occurring concurrently.
- It is apparent from discussions with stakeholders that Systemic Advocacy efforts are currently fragmented across geographic areas, jurisdictions, disability types and advocacy models. Although this problem has been recognised by the advocacy sector, initiatives to improve the coordination of Systemic Advocacy, such as state/territory and national advocacy networks are not yet sufficiently developed in all jurisdictions.

**Efficiency of the Advocacy Models**

**Comparative Cost:Benefit of Advocacy Models**

- An advocacy model that focuses primarily on Individual Advocacy but has the flexibility to use or refer to other approaches (e.g. Self Advocacy, Legal Advocacy or Family Advocacy) as needed by an individual from time to time, appears to offer the highest cost:benefit on a total population basis, although this cannot be confirmed due to the lack of accurate and comparable cost and outcome data.
- Other models may also produce significant benefits in individual cases; however, at a national program level, the greatest overall benefit from a finite budget allocation for all Australians who have a disability is most likely to be achieved from primary use of an Individual Advocacy approach.
- Flexibility to use or refer to other approved models of advocacy when required in order to address individual needs, preferences or circumstances, will further enhance this Individual Advocacy approach.
- Systemic Advocacy may be contentious, for example, it may involve advocacy agencies criticising the policies or programs of a department or government that provides funding. It is important, however, to have a process for identifying and addressing systemic issues, barriers or other problems encountered by people with disability.
• A mechanism(s) and pathway(s) are needed for Individual Advocacy issues, particularly those issues that cannot be readily resolved or that occur repeatedly, to feed through Systemic Advocacy to state/territory or Commonwealth government policy agenda.

Suggestions for Improving the Efficiency of Advocacy Resources
• Stakeholders’ suggestions for improving the utilisation of advocacy resources include:
  • collaboration and sharing and pooling resources
  • reviewing administration arrangements, such as office location, group purchasing for insurance, etc.
  • a three-year funding cycle to assist with issues such as forward planning, staff retention and leasing of premises.
  • increased use of technology
  • simplifying data collection and reporting arrangements
  • use of pro bono supports.

Extent to which the Advocacy Models Collaborate and Feed into Public Policy

Advocacy Input to Public Policy
• Systemic Advocacy is the main model which inputs to public policy. Legal Advocacy also has a role, particularly in respect of legislation.

• Many advocacy agencies report some degree of involvement in public policy, for example, participation in consultation processes, membership of advisory committees, and referral of issues for Systemic Advocacy or Legal Advocacy attention. This involvement is spread across the various advocacy models, although Citizen Advocacy has a less formal role in this respect.

• At present, the effectiveness and efficiency of Systemic Advocacy in Australia is reduced by fragmentation, wide dispersion of limited resources for Systemic Advocacy, lack of coordination and the need for a more effective linkage with Individual Advocacy and with government information and reporting systems.

Collaboration and Networks
• Most of the advocacy agencies consulted expressed a desire for good collaboration with other advocacy agencies and models. Some were able to describe examples of collaborative and complementary practice. These examples included: provision of specialist advice to other advocacy agencies and/or mainstream services; referral of individuals to other advocacy agencies or models where these were better suited to the individual’s needs; working in collaboration with organisations such as community legal centres; and sharing of information or knowledge between advocacy agencies.

• Networks of advocacy agencies have been formed in the larger jurisdictions for the purposes of information sharing, training and development. A national
network (the Disability Advocacy Network of Australia) has also recently been formed and has received some seed funding from FaHCSIA to assist in its development.

- Current limitations in collaboration between advocacy models and agencies include:
  - insufficient resources and competing demands limiting the administration of collaborative network structures and the frequency of meetings and conferences
  - distance and cost barriers restricting participation of regional/rural advocacy agencies in collaborative network meetings and events
  - limited awareness amongst advocacy agency staff, particularly in the larger jurisdictions, of other advocacy agencies and their roles, specialisations, and target groups.
  - ideological differences between some advocacy models or agencies.

**Meeting Present and Future Needs**

- Although many advocacy agencies consider that the model(s) of advocacy that they use are appropriate, there was support from discussion groups for a less arbitrary use of the six models in the funding of advocacy services and for a more flexible approach.
- Stakeholders have described a number of gaps in the distribution of advocacy services across Australia in terms of an absence of disability advocacy services in some geographic regions and lack of access to specialist advocacy supports for particular populations in some areas.
- Stakeholders are concerned that limited funding and resources, inadequate networking and linkages and variable quality of advocacy service provision are limiting the ability of advocacy agencies to meet the needs of people with a disability.
- Advocacy agencies have identified the need for training for advocacy staff and there is support for national standards of advocacy practice.

**Suggested Modifications to NDAP**

- There is general agreement that NDAP aims should be clearly defined and that the program and its funding should focus on outcomes rather than on models of advocacy.
- Stakeholders suggest that the most vulnerable people with disability should be a priority focus of the NDAP.
- The NDAP should aim to clarify what advocacy is and have consistent principles and guidelines on which provision of advocacy support is based.
- There is considerable support, including support from FaHCSIA state and territory officers, for funding two main streams of advocacy, namely Individual and Systemic. A more flexible definition of Individual Advocacy should include the use of other advocacy models for individuals where appropriate.
• There is support from advocacy agencies for continued diversity in the range of advocacy models and the availability of specialist advocacy services for particular groups, for example, people with mental illness or those from CALD or ATSI backgrounds.

• There is no consensus view regarding the merits of having a mix of Individual and Systemic Advocacy within single advocacy agencies.

• The current NDAP funding arrangements where small allocations for Systemic Advocacy are spread across a number of advocacy agencies are not ideal and the effect of this dispersion is that many agencies do not have sufficient resources to adequately or effectively pursue systemic issues.

• Stakeholders suggest that FaHCSIA should fund specific Systemic Advocacy agencies in each state/territory and nationally and better utilise the existing national peak disability bodies to identify and respond to systemic issues.

• Stakeholders have proposed several options for a structure and mechanism to feed systemic issues through from Individual Advocacy to state/territory and national Systemic Advocacy organisations.

• There is widespread support for stronger collaboration and information sharing between advocacy agencies.

• There is a need for improved and nationally consistent training of advocates, improved advocacy content in general disability sector training courses and a need for regular governance training for members of boards of management in advocacy agencies.

• The role of disability advocacy and advocates needs to be promoted to people with disability, their families, service providers and the general community.

• A three-year funding cycle would assist advocacy agencies in forward planning, administrative arrangements and staff retention.

• More consistent and streamlined reporting requirements across state/territory and Commonwealth government funders could release more advocacy agency resources for advocacy service provision.

• The advocacy sector needs and wants consistent advocacy practice standards and a national quality assurance and accreditation process.

**Indicators of Success for the NDAP**

• Although stakeholders found it difficult to suggest measures or indicators that the government should use to evaluate the success of the program at a national level, there was acceptance that some quantitative measures would be needed. There was consistent support for the use of qualitative information.

• A key concern about the use of quantitative indicators, such as the number of consumers receiving advocacy support, is that basic counts do not distinguish between brief episodes of support and more complex and lengthy assistance.

• FaHCSIA’s Standard Performance Management Framework for Community Services Funded Programs (April 2009) specifies the use of several indicators from a range of generic indicators. This research project has identified the
specified indicators that would be most appropriate for the NDAP. Additional indicators have been suggested for Systemic Advocacy.

Overall Conclusions
A review of the research literature and consultations with stakeholders strongly indicate that the NDAP should fund two main streams of advocacy: Individual Advocacy and Systemic Advocacy.

Individual Advocacy should be the primary model of advocacy for the NDAP but should incorporate the flexible use of other models such as Self Advocacy, Legal Advocacy and Family Advocacy as appropriate to meet consumer needs.

Specialist advocacy support should continue to be provided for people whose advocacy needs require specialist knowledge and skills, for example, people with mental illness and complex needs or people from CALD or ATSI communities. All advocacy staff should have at least basic cross-disability knowledge and cultural awareness.

Individual Advocacy agencies should have clear linkages to Systemic Advocacy at state/territory and national levels. There should be a structured pathway(s) for systemic issues identified by Individual Advocacy agencies to progress through Systemic Advocacy agencies to government policy agenda.

The national disability advocacy system should be founded on:

- consistent advocacy principles and standards of practice
- national disability advocacy quality assurance and accreditation processes
- collaboration and networking between advocacy agencies
- accredited training and development opportunities for advocacy staff.

Recommendations
Having carefully considered the information and findings from all of the research activities undertaken for this project, including the views expressed by all stakeholders who participated in consultations, the research team makes the following recommendations:

Recommendation 1
FaHCSIA should clearly define the aim of the National Disability Advocacy Program with the focus of the program to be on outcomes for individuals with priority to the most vulnerable people with disability.

Recommendation 2
FaHCSIA should develop an agreed set of principles and program guidelines on which advocacy funded through the National Disability Advocacy Program will be based.
Recommendation 3
FaHCSIA should fund two main streams of advocacy through the National Disability Advocacy Program: Individual Advocacy and Systemic Advocacy.

Recommendation 4
Individual Advocacy should be the primary model of advocacy funded through the National Disability Advocacy Program. Each agency funded to deliver Individual Advocacy should provide individual consumers with advocacy assistance undertaken by a trained advocate. Individual Advocacy for the purposes of NDAP should have a flexible definition enabling the additional use of, or referral to, a range of other advocacy models, such as Self or Legal, as required by consumers from time to time.

Recommendation 5
FaHCSIA should review the geographic map of advocacy services currently funded by Commonwealth and State/Territory governments to identify gaps in the availability of advocacy services.

Recommendation 6
FaHCSIA should review the current allocation and distribution of Systemic Advocacy resources. Over time, FaHCSIA should allocate NDAP funding for Systemic Advocacy to ensure that agencies funded to provide Systemic Advocacy have sufficient resources to effectively manage systemic issues and there is at least one Systemic Advocacy agency in each state and territory.

Recommendation 7
In consultation with the advocacy sector, FaHCSIA should develop a process for Individual Advocacy agencies to identify issues requiring Systemic Advocacy and a pathway(s) to feed these issues through to the appropriate Systemic Advocacy organisations at state/territory and national levels and on to state/territory and/or Commonwealth government policy agenda.

Recommendation 8
In consultation with the advocacy sector, FaHCSIA should facilitate a National Systemic Advocacy Forum involving representatives of a national disability advocacy peak organisation, state/territory advocacy networks, national disability peak bodies (including consumer representatives) and relevant government representatives to consider systemic issues, examine supporting evidence, prioritise issues and provide appropriate input to government policy agenda.

Recommendation 9
The disability advocacy sector should facilitate regular professional development, collaboration and networking opportunities for disability advocates and governance training for Board members.
Recommendation 10
The disability advocacy sector should work with the Community Services and Health Industry Skills Council and State Training Authorities, to revise and improve the disability advocacy training standards contained in the Community Services Training Package.

Recommendation 11
FaHCSIA, state and territory governments and the disability advocacy sector should improve the advocacy information for consumers and advocates provided on government and agency websites and in other media. This information should include names and locations of government-funded advocacy agencies, types of assistance provided, agency contact details and links to networking and development opportunities for advocates.

Recommendation 12
FaHCSIA should consider introducing a three-year funding cycle for NDAP-funded advocacy agencies and ensure that funding agreements allow for sufficiently flexible advocacy responses to meet individual and community needs.

Recommendation 13
FaHCSIA should continue discussions through Commonwealth/State/Territory mechanisms with a view to addressing inconsistencies between Commonwealth and state/territory government funding policies and reporting requirements for advocacy agencies.

Recommendation 14
FaHCSIA should consider introducing a simple classification of level of advocacy support for the purposes of reporting the number of advocacy consumer contacts. This classification should differentiate between simple advocacy assistance such as brief telephone advice, information or referral and more complex and resource intensive levels of advocacy support.

Recommendation 15
FaHCSIA should continue with the process to trial National Advocacy Standards and an associated Quality Assurance and accreditation system.

Recommendation 16
FaHCSIA should use the following performance indicators from the Standard Performance Management Framework for Community Services Funded Programs (FaHCSIA, April 2009) to evaluate and report on the NDAP at a national level:

- Satisfaction with assistance received (B1.1) – Percentage of clients satisfied that the service they received met their needs.
- Participation and coverage (C1.2) - Number/percentage of clients assisted by geographical location
- Service quality (C3.4) – Percentage of service providers who meet accreditation requirements or relevant industry standards for service management and governance
• Service outputs (D1) – Number of clients assisted (per year) by output category.

Recommendation 17

FaHCSIA should consider using the following performance indicators to evaluate and report on Systemic Advocacy at a national level:

• Number of Systemic Advocacy issues on which progress has been achieved during the reporting period.
• Number of Systemic Advocacy issues which have been resolved or finalised during the reporting period.
• Percentage of Systemic Advocacy issues for which an action plan and/or critical pathway or program logic model has been prepared.
• Percentage of Systemic Advocacy issues which are supported by evidence and/or referrals from Individual Advocacy agencies.

These quantitative measures should be complemented by qualitative information including case studies, success stories and examples of best practice.

Figure 1 overleaf illustrates the flow of systemic advocacy issues from individual consumers to government policy agenda that should occur if the recommendations of this research project are implemented.
Figure 1  Recommended Flow of Systemic Advocacy Issues

National Disability Advocacy Program
Recommended Flow of Systemic Advocacy Issues

Issues to Commonwealth Government Policy Agenda

National Systemic Advocacy Forum
- National Disability Advocacy Peak Body
- State/Territory Advocacy Networks
- National Disability Peaks
- Government representatives

National analysis of NDAP report data

Issues to State/Territory Government Policy Agenda

Systemic Advocacy Agencies
- State/Territory Level

Collaboration on Group and Localised Systemic Issues

Individual Advocacy Agencies
- Flexible use of Individual, Self, Legal, Family, Group Advocacy
- Accessible to people with disabilities in all geographic areas

Specialist Advocacy Agencies
- e.g. Psychiatric disability, CALD, ATSI, Legal providing assistance to generalist Individual Advocacy agencies as required

Agreed Principles of Advocacy and National Quality Standards

INDIVIDUAL CONSUMER ISSUES
1.0 Introduction

This is the final report of research regarding the six models of advocacy currently funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) under the National Disability Advocacy Program (NDAP). The research was conducted by Jenny Pearson & Associates Pty Ltd.

1.1 Background

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

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>
</tr>
</thead>
<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 General descriptions sourced from National Disability Advocacy Program Consultation Work Sheets, FaHCSIA, 2008.
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.

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.\(^3\)

Previous reviews of NDAP have focussed on the program as a whole. The six models of advocacy have evolved over time in line with global trends and there has been no specific Australian research to examine the application and outcomes of the different models of advocacy that are now funded under NDAP.

The purpose of this research was to examine the appropriateness, effectiveness and efficiency of the six models of advocacy and to develop key performance indicators that could be used to measure the success of the different advocacy models now and in the future. The research also explored the interactions and linkages between the different models of advocacy, how these feed into Systemic Advocacy at the State and national levels and how Systemic Advocacy influences public policy.

The research aimed to enable FaHCSIA to better understand:

- the linkages between the different disability advocacy models
- how the models can be strengthened to work together to promote positive systemic change
- how the models can effectively assist and support each other to provide a more whole-of-life response to the issues that people with disability encounter.

\(^3\) NDAP Information and Consultation Session, FaHCSIA, March 2008
1.2 Research Requirements

The broad requirements for the research were to:

- Develop a research design and methodology, including a work plan, suited to the requirements of the project to meet its objectives.
- Undertake a literature review of relevant advocacy models of support for the target population in Australia and overseas.
- Develop key performance indicators to measure the appropriateness, effectiveness and efficiency of the different models of advocacy support.
- Prepare a draft research report which includes:
  - a description of the methodology
  - literature review
  - an assessment of each model of advocacy against the key performance indicators developed
  - response to the Key Research questions
  - a comparative analysis of the six models
- Prepare a final research report to the satisfaction of the Department.

The Key Questions to be addressed in this research were as follows:

Q1: How effective are the six advocacy models in achieving the aims of the program?
   The research shall consider:
   a) the circumstances where each model achieves a positive outcome for the consumer;
   b) the circumstances where each model doesn’t achieve a positive outcome for the consumer;
   c) barriers to the models achieving positive outcomes;
   d) strategies to overcome the barriers; and
   e) how effectively each model contributes to systemic change.

Q2: How appropriate are the six advocacy models?
   The research shall consider:
   a) whether the models are relevant to the present and future needs of Australians with disability; and
   b) any modifications that need to be made to the models to meet current and future needs.

Q3: How efficient are the advocacy models of support?
   The research shall:
   a) consider the cost of each model and its benefits to the population target group;
   b) consider the duration and intensity of support required under each model to achieve positive outcomes and outputs for people with disability and public policy; and
   c) critically review each model and advise of the most efficient model(s).
Q4: To what extent do the different models collaborate and feed into public policy?

In considering this, the research shall have regard to:

a) the effectiveness of the different models in feeding into public policy;

b) the extent and effectiveness of the models in collaborating and complementing each other in practice; and

c) the extent to which the specialist services share their knowledge to support generic services.

The research was conducted from late April to the end of June 2009.

1.3 Structure of this Report

The methodology used for the research is described in Section 2.0. A brief profile of the NDAP program prepared from quarterly report data follows in Section 3.0. A summary of the issues and findings from the review of the research literature is presented in Section 4.0 with the full review paper including bibliography provided in Appendix A.

Key findings from the research consultations in respect of each of the four research questions are presented in sections 5.0 through 8.0. A brief conclusion appears at the end of each section.

To provide a logical flow to the report, the research questions are addressed in the following order: Research Question 1 (Section 5.0), Question 3 (Section 6.0), Question 4 (Section 7.0) and Question 2 (Section 8.0).

Finally, Section 9.0 documents the conclusions and recommendations of this research project.

Stakeholders contributed a large amount of information to this research project through discussion groups, interviews and submissions. A representative selection of these comments is included to illustrate the range of stakeholder views while having regard to the length and readability of the report.
2.0 Project Methodology

The methodology for this research is summarised in Figure 2 and then described in more detail.

Figure 2 Research Methodology
Research into Models of Advocacy Funded under the National Disability Advocacy Program
Summary of Methodology

- Project Start-up
  - Preliminary briefings with FaHCSIA representatives
  - Review of resources/materials

Design Research Plan
- Methodology
- Work Plan

Literature Review
- Advocacy models in Australia and overseas

Develop KPIs to measure
- appropriateness
- effectiveness
- efficiency of advocacy models

Consult with
- Disability advocacy sector
- Peak bodies
- FaHCSIA State and Territory offices
- Other key stakeholders

Review Quantitative Data and Reports
- Performance, utilisation, outcome data
- Financial data
- Previous NDAP evaluation reports
- NDAP QA Consultation report

Phase 1

Literature Review

Phase 2

Develop KPIs to measure

Phase 3

Consult with

Phase 4

Review Quantitative Data and Reports

Phase 5

Analysis of Relationships and Interactions

Phase 6

Prepare Draft Report

Prepare Final Report

Regular liaison and meetings with FaHCSIA representatives
2.1 Project start up

Project start-up involved preliminary briefings with FaHCSIA representatives for this research and the review of resources and materials provided by FaHCSIA to the consultant.

2.2 Design research plan

The consultant developed a Research Plan in consultation with FaHCSIA representatives. This plan described all aspects of the methodology for the research. A detailed work plan was also included, identifying all of the research activities and timeframes for completion.

2.3 Literature Review

Phase 2 of the research involved reviewing the Australian and international literature regarding disability advocacy models used here and overseas.

The literature review particularly focussed on any research or reports relating to the appropriateness, effectiveness and efficiency of different advocacy models or combinations thereof and a comparison of the application of advocacy models in Australia with use overseas.

A specialist disability library assisted with literature searches, interlibrary loans and document retrieval.

A paper documenting the findings of the literature review was submitted to FaHCSIA. (Refer Appendix A)

2.4 Develop Key Performance Indicators

Phase 3 of the research involved the development of key performance indicators (KPIs) to measure the appropriateness, effectiveness, efficiency and overall success of the advocacy models funded under the NDAP.

Consideration was given to indicators and measures identified through the literature review and to FaHCSIA’s Standard Performance Framework for Community Services Funded Programs (Edition 6, April 2009).

2.5 Review Quantitative Data and Reports

The consultant conducted a desk review of quantitative data, reports and other documentation provided by FaHCSIA for this research. This material included:

- NDAP performance, utilisation and outcome data (compilations of quarterly report data from January 2008 to March 2009)
- previous NDAP research reports
- NDAP Quality Assurance Consultation report.
2.6 Consult with Key Stakeholders

Key stakeholders for this research included:

- the disability advocacy sector, particularly NDAP-funded agencies
- peak bodies representing people with disability and their families and carers
- FaHCSIA State and Territory offices, particularly the personnel involved in oversight of NDAP and other advocacy-related initiatives.

Three main methods of consultation were used for this research project:

- interviews by phone and face-to-face with individual organisations and stakeholders
- discussion group sessions with advocacy agencies
- an invitation for key stakeholders to submit written submissions to inform this project.

2.6.1 Interviews

The interviews provided one-to-one interaction with the consultant (face-to-face or by telephone) for key stakeholders such as peak bodies in the disability sector and FaHCSIA national or state/territory office staff who have oversight or other responsibilities with NDAP.

The interview questions/discussion points explored the Key Research Questions and identified any other information or documents that might be useful for the research. The interview content was tailored to specific stakeholders as appropriate. (Refer to Appendices B and C for the interview questions that were used to guide interviews with peak body representatives and FaHCSIA state/territory office staff respectively.)

The consultant interviewed 22 stakeholders for this research project. Sixteen of the interview participants were FaHCSIA state/territory officers with experience of the NDAP, five were staff of NDAP-funded advocacy agencies located in rural/regional areas or states where discussion groups were not held, and one interviewee represented a peak disability body.

2.6.2 Discussion Group Sessions

Discussion group sessions for advocacy agencies funded under the NDAP were conducted in Melbourne, Sydney, Brisbane, Adelaide and Perth.

The topics for discussion were similar to those for the interviews and the discussion group process enabled the issues to be explored and developed with the participants. (The discussion group questions/handout appear in Appendix D to this report.)

The discussion groups were each of approximately four hours’ duration with lunch provided. These sessions were held from mid-May to early June 2009. FaHCSIA representatives attended the groups to assist the research consultant and hear the discussions first hand.

Attendance numbers for each discussion group are shown in Table 1.
Table 1  Number of Discussion Group participants from NDAP-funded advocacy agencies

<table>
<thead>
<tr>
<th>Discussion Group Location</th>
<th>No. of Participants from NDAP-funded Advocacy Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sydney *</td>
<td>13</td>
</tr>
<tr>
<td>Melbourne</td>
<td>12</td>
</tr>
<tr>
<td>Adelaide</td>
<td>5</td>
</tr>
<tr>
<td>Perth</td>
<td>12</td>
</tr>
<tr>
<td>Brisbane</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>50</strong></td>
</tr>
</tbody>
</table>

* The Sydney group included some participants from advocacy agencies in the ACT and Tasmania

2.6.3 Submissions

FaHCSIA informed NDAP-funded advocacy agencies of this research project by email and letter. This correspondence advised agencies of the schedule of discussion groups and also included an invitation to provide written submissions to the project. A proforma for submissions was provided to guide the written responses. (Refer to Appendix E)

The proforma included specific topics or research questions and requested a limited amount of non-identifying demographic data to enable a profile of respondents to be described.

FaHCSIA also advised the relevant peak bodies in the disability sector of the research project and invited these organisations to provide a written submission and/or to participate in an interview with the research consultant. A proforma for submissions was also provided to this group. (Refer Appendix F)

Submissions were returned by email or post direct to the research consultant using a Reply Paid address. A Freecall telephone number was also provided by the consultant for telephone interviews and enquiries about the project.

A total of 27 submissions were received: 19 from NDAP-funded advocacy agencies, 7 from disability peak bodies and one from an individual.

2.7 Analyse Qualitative Data from Interviews, Discussion Groups and Submissions

Phase 4 of the research involved collation and analysis of the qualitative data from stakeholder interviews, discussion groups and submissions. The interview, submission and discussion group questions were linked to the key research questions. This increased the utility and relevance of information received from stakeholders and facilitated analysis and reporting of this data.
2.8 **Respond to the Key Research Questions and Undertake Comparative Analysis of the Six Advocacy Models**

At this stage of the project, the research consultant had collected and analysed all of the required qualitative and quantitative data relating to the six advocacy models funded under NDAP. The first three Key Research Questions specified in the terms of reference concerned the effectiveness, appropriateness and efficiency of the advocacy models. These research questions were considered as the consultant undertook a comparative analysis of the six advocacy models.

2.9 **Analyse Relationships and Interactions between the Models**

The fourth research question related to the relationships and interactions between the six advocacy models and how the different models feed into public policy. The consultant analysed and reported on these relationships and interactions.

2.10 **Develop Recommendations**

Having responded to the key questions for the research, the consultant drafted initial recommendations in consultation with FaHCSIA. A workshop meeting with FaHCSIA representatives was convened to report on the main findings of the research and to discuss potential recommendations.

2.11 **Prepare Draft and Final Research Reports**

The consultant then prepared a draft research report which included:

- background and terms of reference for the research
- a description of the research methodology
- report of the literature review
- responses to the Key Research Questions
- a comparative analysis of the six models
- recommended key performance indicators
- conclusions and recommendations

The draft research report was submitted to FaHCSIA for feedback to complete Phase 5 of the project.

Once feedback from FaHCSIA is received, the research report will be finalised and submitted and this will complete the final phase of the project.
3.0 Profile of the National Disability Advocacy Program

The information presented in this section is derived from quarterly report data provided by NDAP-funded advocacy agencies to FaHCSIA. There are a number of limitations to this data, including:

- changes that have occurred to the data set over the past two years which mean that a full year of comparable data is not available
- inconsistencies in reporting resulting in incomplete data for some items.

Many of the NDAP-funded agencies also receive funding from other sources, including state/territory governments. It cannot be assumed that all agencies are able to consistently and accurately assign advocacy costs and outcomes to specific funding programs.

3.1 Number and Distribution of NDAP-funded Advocacy Agencies

In the 2008-09 financial year, there were 63 NDAP-funded advocacy agencies. The distribution of these agencies by state and territory is shown in Table 2.

Table 2 Distribution of NDAP-funded Advocacy Agencies by State/Territory in 2008-09

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>Number of NDAP-funded Advocacy Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>2</td>
</tr>
<tr>
<td>NSW</td>
<td>14</td>
</tr>
<tr>
<td>NT</td>
<td>3</td>
</tr>
<tr>
<td>QLD</td>
<td>7</td>
</tr>
<tr>
<td>SA</td>
<td>6</td>
</tr>
<tr>
<td>TAS</td>
<td>3</td>
</tr>
<tr>
<td>VIC</td>
<td>20</td>
</tr>
<tr>
<td>WA</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>63</td>
</tr>
</tbody>
</table>

3.2 Advocacy Models Used

Based on quarterly report data from October 2008 to March 2009 inclusive, NDAP-funded agencies manage over 23,000 consumer issues per year.

Most of the NDAP-funded advocacy agencies use a mix of advocacy models. Individual Advocacy is by far the most frequently reported model and is used for more than two-thirds of all consumer issues. Family Advocacy, Citizen Advocacy, Legal Advocacy and Self Advocacy models are used in 6 per cent to 9 per cent of consumer issues. Refer to Figure 3.
Figure 3  Proportion of Consumer Issues by Advocacy Model Used

3.3 Profile of Consumers

Projecting from October 2008 to Mar 2009 quarterly report data, NDAP-funded advocacy agencies provide advocacy support for over 7500 new consumers per year and give continuing support to almost 2500 ongoing consumers each quarter.

At least 17 per cent of the people who receive advocacy support are from culturally and linguistically diverse backgrounds and 7 per cent are Aboriginal or Torres Strait Islander people.

People who have an intellectual disability represent just over one-third (36 per cent) of consumers of NDAP-funded advocacy support, followed by people with physical disability (17 per cent) and people with psychiatric disability (13 per cent). Refer to Figure 4.

Note that these numbers are reported each quarter and include both new and ongoing consumers. Consumers receiving longer term advocacy support that extends over more than one quarter may be counted more than once.
3.4 Consumer Issues

Consumers present with a range of issues requiring advocacy support. Data extrapolated from the October-December 2008 and January-March 2009 quarterly reports indicates that over 23000 issues are worked on by NDAP-funded advocacy agencies in a year. Legal issues, service issues (gaps, access, policy, reduction of service or complaints), and accommodation issues account for almost one third of all issues. The profile of consumer issues is shown in Figure 5.
3.5 Advocacy Interventions

Advocacy agencies respond to consumer issues with a range of interventions. The profile of these interventions is shown in Figure 6. This data is extrapolated from the October 2008 to March 2009 quarterly reports. Note that more than one type of intervention may be used for a single consumer issue, so the total number of interventions is greater than the total number of consumer issues.

Direct advocacy support is the most frequent type of intervention, representing just over one-third (34 per cent) of all interventions.
NDAP-funded citizen advocacy agencies report conducting over 2300 follow-up contacts with volunteer advocates each year, assisting volunteer advocates to provide an intervention on behalf of a protégé on over 790 occasions a year and training almost 100 citizen advocates. (Based on extrapolation of October 2008 to March 2009 quarterly report data). During this period, there were approximately 100 people with disability waiting to be matched with a citizen advocate in each quarter.

The quarterly report data indicates that NDAP-funded advocacy agencies are working on approximately 200 systemic advocacy actions in a quarter, with over 300 positive outcomes achieved in a year.

### 3.6 NDAP Funding

A total of $11,780,376 (excluding GST) was provided to advocacy agencies through the NDAP in the 2007-08 financial year. The amounts provided to individual advocacy outlets ranged from $50,389 to $439,157 with an average annual funding grant of $175,827.

Any attempt to provide a comparative analysis of the cost of advocacy supports across advocacy agencies or models using the quarterly report data is fraught with difficulties and limitations. Whilst the funding provided to each agency by the NDAP is known, the isolation of this funding from other funding sources is unknown. The mixed use of models within most agencies makes attribution of funding and consumer outcomes to specific advocacy models almost impossible. There is also significant uncertainty regarding the methods and accuracy of agencies’ collection of data on consumer numbers.
A detailed and well-controlled costing study would be needed to obtain more reliable data but this would be a very resource-intensive exercise for what may be a limited benefit.

The following findings therefore need to be considered in the context of the limitations outlined above.

Based on quarterly report data from 2007-08, advocacy agencies spent an average of $721 of NDAP funding per advocacy consumer per quarter. Some agencies significantly exceeded this average amount per consumer while others were below this benchmark. Note that we do not have information regarding funding that advocacy agencies receive from other sources, such as state/territory governments, so this is not a calculation of total cost per consumer.

There was no particular pattern in terms of the comparative cost-effectiveness of different advocacy models. Of the two most expensive advocacy agencies (in terms of NDAP funding), one used predominantly Individual Advocacy while the other was a Citizen Advocacy agency. Of the outlets that primarily used an Individual Advocacy model, 21 were below the average cost per consumer and 15 were above average cost. Two Citizen Advocacy agencies were above the average cost but seven were below the average cost.
4.0 Summary of Issues and Findings from Review of the Research Literature

A review of Australian and overseas research literature was conducted as part of this research project. The complete review paper including bibliography is provided as Appendix A to this report. A summary of the main issues and findings is presented below.

4.1 Models of Advocacy used Overseas

The models of advocacy most commonly used in other countries are:

- Self Advocacy – usually in a group context, such as the ‘People First’ movement and described by some authors as a social movement
- Citizen Advocacy as founded by Wolf Wolfensberger
- Individual Advocacy with the use of paid advocates funded by government and/or charitable organisations
- Legal Advocacy
- Family Advocacy – in some programs involving parent advocacy or peer advocacy rather than the model defined in the NDAP
- Systemic Advocacy.

The majority of the published research concerning specific models of advocacy focuses on Self Advocacy or Citizen Advocacy. Most studies conclude in favour of these respective models.

There is a strong emphasis in the advocacy research on Independent Advocacy with many examples of government funders commissioning independent providers in order to minimise conflict of interest.

4.2 Effectiveness of Advocacy Models

The research literature identifies a number of concerns about the effectiveness of disability advocacy including:

- inadequate strategic planning
- aims not clearly defined
- under-funding and under-staffing
- lack of shared issues amongst the disability community
- restrictive funding conditions and short-term grants creating uncertainty, increasing staff turnover and increasing bureaucratisation
- funding from statutory sources potentially compromising the independence of advocacy program.

There is little research regarding the comparative effectiveness of the different advocacy models. The few findings that are published suggest that:
• Individual Advocacy is far less costly than Legal Advocacy.
• Individual Advocacy is particularly effective for short-term and urgent intervention for vulnerable people with disability.
• Self Advocacy has its greatest impacts on the members of self advocacy groups including gains in confidence, self-esteem, assertiveness and communication skills, but questionable success in protecting other people with disability. Good facilitative support is important for this model. Self Advocacy should not be the only form of advocacy available to people with disability.
• Citizen Advocacy can be successful in providing stable advocacy to individuals over a long timeframe if advocate/protégé matches can be made and sustained. One study found that more than half of the matches made in Australian Citizen Advocacy programs may be lost. The effectiveness of Citizen Advocacy may also be dependent on effective Boards of Management and staff, resourcing for regular evaluation against the CAPE standards, and the presence of other forms of advocacy in the community. Citizen Advocacy programs may fail for reasons that are not always clear. Citizen Advocacy should be accompanied by other models of advocacy, including access to formal and Legal Advocacy if needed.

A number of authors have concluded that there are advantages in having a range of forms and types of advocacy available and that people will often require more than one type of advocacy.

Suggestions found in the research literature for improving the effectiveness of advocacy in general include:
• better resource bases
• more focussed policy concerns
• improved strategic links and communication networks between advocacy agencies
• skilled leadership
• sufficient autonomy to act in a timely manner
• a distinct and recognisable organisational identity.

4.3 Methods of Evaluating Advocacy
The research literature presents good rationale for evaluating advocacy schemes but notes a lack of evidence on the effectiveness and use of evaluation models for advocacy. For example, research conducted in the United Kingdom found that the majority of advocacy schemes were evaluated through service level agreements and/or annual reports and only six per cent of surveyed schemes used an accredited evaluation tool. (Hussein et al, 2006)

The literature describes a number of methodological challenges in evaluating advocacy programs, including:
• difficulties in measuring the social justice outcomes of advocacy
• the complexity of public policymaking
• the role of external forces and conditions
• problems of attribution, i.e. determining cause and effect
• the long time frames needed for systemic changes
• lack of commitment to and resources for evaluation.

The Citizen Advocacy Program Evaluation (CAPE) instrument has been designed specifically for evaluating Citizen Advocacy programs. Other advocacy evaluation tools or models described in the research literature include:

• ANNETTE – an outcomes-focused tool which uses tables to count the number of advocacy tasks undertaken, time taken to complete tasks and the nature of different advocacy roles.
• Guidelines developed by the Scottish Executive and promoted by the Advocacy Safeguards Agency which identify core criteria for the evaluation of all forms of advocacy and specific criteria for particular case scenarios.
• Citizen Advocacy Information and Training (CAIT) which has a process involving interviews of Citizen Advocacy partnerships and staff conducted by a CAIT evaluation team.

Other evaluation frameworks have been less frequently applied and are often one-off evaluation methodologies used for specific projects.

In Australia, the Commonwealth and Queensland State governments, in consultation with stakeholders, have developed a Strategic Reporting Framework for all government-funded disability advocacy organisations in that state. At the national level, FaHCSIA is soon to trial a quality assurance system for the National Disability Program.

Some recent research has been conducted in the field of program logic or ‘critical path analysis’ for advocacy programs, i.e. advocacy organisations would have a theory of change underlying their work and a flow chart or similar representation would be used to demonstrate how change is achieved and what steps are required. Evaluation may include linking outcomes to a theory of change and focussing on the achievement of intermediate steps required for long-term social and policy change.

The literature suggests that no single model of evaluation can be applied to every type of advocacy. Less tangible outcomes will need to be measured, for example, shifts in social norms and impact on the target group.

4.4 Standards and Performance Indicators

There is a small amount of literature regarding the use of standards for advocacy organisations but few specific suggestions in respect of performance indicators. Some papers describe the difficulties in identifying effective performance indicators for advocacy.

One research paper recommends that advocacy standards should address at least the following areas:

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, 1993)

Standards for disability advocacy in Australia have been developed by the Commonwealth Government and in Queensland by the State Government. Evaluation of the implementation of these standards is yet to occur.

4.5 A Framework for Advocacy Programs in Australia

Researchers have expressed concern about the focus on models of advocacy in Australia and have suggested a more broad-based and systemic approach. Complementary roles for both individual and systemic advocacy have been identified and the research also suggests that a diversity of advocacy models is required. This diversity will not only provide appropriate responses to the wide range of disabling barriers but will also ensure that both short-term issues and long-term changes are addressed.

The research further recommends that the linkages between individual and systemic advocacy should be nurtured and that the key to this will be to strengthen networking and referral between advocacy groups.

In addition to suggesting research and development activities, education, training, promotional activities, standards, quality measures, and evaluation in the advocacy sector, Cocks & Duffy (1993) also recommend a mechanism in each state and territory to identify local advocacy priorities and a mechanism at the national level to address national advocacy issues and make recommendations to the appropriate Minister.

Conclusions

The research literature is inconclusive in respect to the relative effectiveness of each 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 disability
- the need for specific resources dedicated to systemic advocacy (quarantined from the resource demands of individual advocacy)
- the importance in advocacy organisations of focused policy aims, better resource bases and skilled leadership
- the potential advantages of linkages between advocacy agencies and a coordinated, collaborative approach to prioritising and addressing systemic issues
• 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 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 and Legal Advocacy.

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

As will be seen in the following sections, the literature review supports many of the issues and suggestions identified by stakeholders in the consultations conducted for this project.

Please refer to Appendix A for the full text of this review of the research literature and the associated bibliography.
5.0 Key Findings regarding the Effectiveness of the Six Models of Advocacy

This section of the report details the research findings in respect of Research Question 1.

Research Question 1: How effective are the six advocacy models in achieving the aims of the program?

The research shall consider:

a) the circumstances where each model achieves a positive outcome for the consumer;

b) the circumstances where each model doesn’t achieve a positive outcome for the consumer;

c) barriers to the models achieving positive outcomes;

d) strategies to overcome the barriers; and

e) how effectively each model contributes to systemic change.

5.1 Individual Advocacy

The current NDAP definition of formal Individual Advocacy refers to paid advocates employed by an advocacy agency, working with people with disability on a short-term and issue-specific basis. Advocacy agencies report that this work can involve the use of a range or combination of advocacy models and approaches.

Individual Advocacy covers everything. We use all types of advocacy. (Discussion group participant)

We use strategies, not models. We may use a combination of approaches. (Discussion group participant)

There was also acknowledgement that a specific model may be needed at times, for example, where there is a need for ongoing one-to-one advocacy.

Some discussion groups suggested that Individual Advocacy agencies address more difficult and complex needs.

Individual Advocacy will deal with people or matters that no-one else will take on. It would be very hard to get volunteers for many of these situations and they would need a very high level of training. (Discussion group participant)

Advocacy agencies specialising in assistance for people with disability from ethnic communities described how working with families was a very important part of Individual Advocacy in these communities. The central role of families in many cultures was seen as an important pathway to advocating for the individual with disability. Much of this advocacy was reported to involve linking families and the person who has a disability into the service system, with many having no knowledge of their entitlements. The advocate’s role as ‘cultural broker’ was also described. One agency, for example, has Muslim staff who can work with these communities.
Individual advocacy with CALD clients frequently involves working with their families/carers and cultural communities, and the resulting advocacy often is a mix of individual advocacy with family/carer involvement when required. (Submission from NDAP-funded advocacy agency)

A similar role was described by an agency providing Individual Advocacy support to Indigenous people.

In Indigenous communities, advocates play a role in the life of people with a disability, linking with other services. The advocate helps those who would never read information. People are not aware of the help or services that are there. You need to go to some consumers. (Discussion group participant)

There was a sense from the agencies providing Individual Advocacy support that they are being presented with a very broad range of consumer issues.

... in a small agency that focuses on people with intellectual disability, the issues that arose in 1 month include accommodation, employment, civil legal, victims of crime, alleged offenders, child protection issues, individual funding packages, service access to generic & specialist disability service providers, health, aged care, potential fraud by attendant carers & conciliation with a health service provider. This diversity of issues tests the expertise & skill of worker, & it is only possible to provide quality advocacy in this environment when there is continuity of staff, that staff are properly supported & have access to other advocacy agencies (& other external sources) for secondary consultation. (Submission from NDAP-funded advocacy agency)

The people we see are often in crisis situations, for example, their power has been cut off, they have to appear in court, they are being abused. Once we meet their immediate needs, we plan with them and decide the next steps. (Discussion group participant)

Advocacy agencies described a variety of success stories resulting from Individual Advocacy, including: assisting people to access suitable accommodation, employment and education; dealing with welfare and financial issues; supporting people in justice system proceedings and tribunal hearings; assisting people who are subjected to restrictive practices in service settings; and generally linking people in to services and supports.

The rights of people with a mental illness are often neglected and in some instances abused in the clinical and non-clinical psychiatric sector. Having an advocate intervene on behalf of the individual ensures protection of their rights and facilitates accountability. (Submission from NDAP-funded advocacy agency)

Stakeholders identified a number of advantages of Individual Advocacy.
Individual Advocacy would be my pick. It offers value for money, better controls of quality, a more immediate response to the individual and is not seen as being as adversarial as Legal or Systems Advocacy.

(Interviewee)

Individual Advocacy . . . is directly connected to the consumer, involves the consumer, understands the issue, and understands the disability. For this reason we believe Individual Advocacy to be the most effective and broad spectrum advocacy model. (Submission from NDAP-funded advocacy agency)

Advocacy agencies suggested that Individual Advocacy was most likely to achieve a positive outcome when:

- a person with disability needs immediate short-term assistance which can be accessed easily
- the advocates are skilled and knowledgeable
- there is adequate time to investigate the consumer’s wishes and needs and establish an advocacy action plan with the consumers
- the advocacy is provided face-to-face
- the advocate can establish collaborative working relationships with other stakeholders that benefit the consumer
- the person or organisation with which the consumer has an issue is cooperative
- there are advocacy development activities such as educating the community about advocacy, or supporting informal advocacy efforts by individuals and groups
- sufficient funding is allocated
- advocacy agencies are able to retain good advocates and nurture their development
- advocates are free from conflict of interest
- both experienced advocates and independent complaints mechanisms are available.

The skills and knowledge of the advocate are important.

The advocate needs to have a clear understanding of the nature of the disability and have a good working knowledge of other community and legal supports and relevant legislation e.g. Disability Services Acts, Disability Discrimination Act, Equal Opportunity Act, as well as the Public Advocate, Guardianship Board processes, etc. (Submission from NDAP-funded advocacy agency)

One interviewee for this research suggested that Individual Advocacy was probably the most appropriate model in rural and regional areas.
5.2 Systemic Advocacy

Advocacy agencies suggested that Systemic Advocacy has the broadest outcomes although these take longer to achieve.

Systemic advocacy provides a mechanism for overall reform of legislation, policies and practices that lead to people with disability being rejected, marginalised, abused and neglected, exploited and violated. It can often take longer to see the process of reform achieved, perhaps than achieving an individual outcome. However once reform is achieved it has greater impact for the greatest number of people who are at risk of abuse and neglect. It clearly is located in the context of early intervention and prevention. (Submission from NDAP-funded advocacy agency)

Advocacy agencies described the flow-on effects from Individual Advocacy to Systemic Advocacy, for example, situations where advocacy support for an individual in cases of unsatisfactory service provision had led to systemic change across an organisation or service system.

A significant proportion of this advocacy agency’s systemic advocacy initiatives are generated from common concerns arising from individual advocacy cases. . . Often consultations with consumers and carers are held to provide input to our submissions . . . (Submission from NDAP-funded advocacy agency)

Some Individual Advocacy agencies reported feeding systemic issues to peak disability bodies, specialist advocacy agencies and/or disability discrimination/complaints bodies.

Systemic advocates described involvement in a range of service, policy and legislative developments and examples of these are listed in Section 5.8, ‘Contribution to Systemic Change’.

We have had some very good successes, including the development of the UN Convention on the Rights of People with Disabilities, the Disability Standards, the establishment of a Human Rights Commissioner for people with disabilities, the amendment of legislation as for example the state Equal Opportunity Act, etc. . . we need more cooperation on a national and State level to be more efficient. (Submission from NDAP-funded advocacy agency)

One interviewee stated that good Systemic Advocacy can lead to reduced need for Individual Advocacy in the future.

5.3 Citizen Advocacy

Citizen Advocacy agencies participating in this research project put forward a number of advantages of this model:

- This model has strong principles which are clearly understood by coordinators and advocates.
Citizen advocates have principal loyalty to the person with disability and are not constrained by conflicts of interest associated with human service affiliations, income or funding.

The Citizen Advocacy process has a highly individualised focus with a one-to-one advocate relationship.

Citizen Advocacy is capable of finding people missed by service systems and agencies: it proactively seeks and finds vulnerable people.

There is good governance and regular review and evaluation using CAPE standards in many agencies.

The long-term duration of the relationships between citizen advocates and protégés has powerful benefits for the protégés.

These long-lasting relationships may go beyond advocacy and provide people with disability with friendship and a sense of belonging.

Citizen advocates provide an unpaid person in the life of the protégé when people with disability increasingly have only paid people in their lives.

Citizen Advocacy provides advocacy support outside normal business hours.

This model has a holistic and flexible approach and can respond to an individual's fluctuating needs over time with varied support strategies.

The strength of this model is the capacity to play a longer term preventative role that reduces the needs for more serious interventions and can assist to break the cycle of recurring issues in a person’s life.

(Submission from NDAP-funded advocacy agency)

(The Citizen Advocacy) Model provides for a transfer of social status and value unlike other traditional paid advocacy. This occurs chiefly because the advocacy role is relational rather than transactional. A Citizen Advocate’s presence in the life of someone who is otherwise surrounded by people in paid roles, changes others’ perception of the value and status of the person with a disability. (Submission from NDAP-funded advocacy agency)

Within any future schema, it is essential to preserve the place of citizen advocacy because it is the only socially inclusive model that recruits consumers who can not refer themselves (or mandate the advocacy) that offers long-term, freely-given relationships and maintains a strong local community focus, while being highly cost-effective and personalised.

(Submission from NDAP-funded advocacy agency)

One Citizen Advocacy agency summarised three important aims of this model:

- Protection
- Prevention
- Inclusion.
Representatives of Citizen Advocacy agencies described identifying the most vulnerable people, i.e. those with characteristics (such being isolated, unable to seek assistance, or having an ageing carer) that would warrant Citizen Advocacy involvement.

Some Citizen Advocacy representatives argued against combining Citizen Advocacy with other models such as Individual Advocacy. They indicated that this would present an inherent conflict with the principles of Citizen Advocacy.

A number of stakeholders raised concerns about the inclusion of Citizen Advocacy in the NDAP. For example:

- It is questionable that citizen advocacy actually fulfils a significant advocacy role. The mentoring and support role that citizen advocacy provides is important but perhaps it should be considered as support for people with disability rather than advocacy. (Submission from NDAP-funded advocacy agency)

- Citizen Advocacy encourages a perception that people with intellectual disability cannot speak up or decide for themselves. This tends to breed reliance rather than independence and capacity of the individual. Perhaps Citizen Advocacy could work if it provided a match for friendship but if an issue came up then a paid professional advocate intervened. We should be offering a professional service from a trained person who can assist the person with a disability to consider the options available and make an informed decision. We are asking people to do a very skilled job – people who don’t have preconceived ideas but recognise the rights of the individual. (Interviewee)

- Citizen Advocacy is a high risk model. It places so much pressure on one person – the citizen advocate. It leaves a big void if the advocate leaves, or has other problems. (Interviewee)

- Citizen Advocacy is not a responsive model because it is reliant on finding a volunteer/protégé match. It may take a year or more to find this match and the person’s immediate needs may not be met. (Interviewee)

- I personally feel very uncomfortable with the Citizen Advocacy model. There are huge political risks for any government that funds Citizen Advocacy. You are recruiting someone to advocate on behalf of a vulnerable person without this being a professional relationship. There is a risk of inappropriate relationships. Citizen advocates are not bound by the same constraints as professional staff. Is their training commensurate with their responsibilities? (Interviewee)

Several stakeholders described the Citizen Advocacy model as ‘ideological’, ‘zealous’, or ‘purist’.
5.4 Legal Advocacy

Legal advocacy is important where an individual is likely to be disadvantaged in either the criminal or family court or in guardianship matters because systems have failed to recognise or accommodate their disability (i.e. inability to comprehend the consequences of their actions or behaviour, have not had the opportunity to be heard or have their wishes considered adequately, or where they may have a legitimate medical defence to charges made against them, etc.). (Submission from NDAP-funded advocacy agency)

Representatives of Legal Advocacy agencies who attended discussion groups for this research project, described a number of supports provided by legal advocates, for example:

- supporting a person with disability at interviews with their solicitor
- explaining and paraphrasing legal information in plain English
- getting to know the person and building trust
- assisting the person in relation to court proceedings, guardianship and administration orders, Centrelink appeals, etc.

One legal advocate described a situation where she had been able to turn around a looming sentence of imprisonment for a person with disability by explaining the circumstances and vulnerability of the person to the court.

Other discussion group participants referred to the systemic role that Legal Advocacy may undertake, for example, in arguing for legislative change, or challenging a case through the courts.

Legal Advocacy may take on a precedent case that may have long-term advantages for people with disability. (Discussion group participant)

Recent trends and changes reported by legal advocates participating in our consultations included:

- increasing need for support in accessing legal advice and assistance
- magistrates showing greater awareness of the advocate’s role
- 19 to 23 year age group appearing to be the most vulnerable in terms of need for legal advocacy support
- people with less severe disability and consequently less access to paid carers and other supports, requiring more legal advocacy.

A submission from a peak body stated that Legal Advocacy was essential in disability because of ongoing discrimination. Another submission, this time from an advocacy agency, described an unmet need for legal advocacy services, with all referrals to a disability discrimination legal service rejected due to conflict of interest and other reasons. Issues requiring legal advocacy included youth court matters, children being
removed from the custody of parents with disability and legal matters which cannot be addressed through the disability discrimination legal service.

5.5 Self Advocacy

For NDAP purposes, Self Advocacy is currently defined as supporting people with disability (predominantly people with 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.

Whilst the NDAP definition of Self Advocacy includes both individual and group-based advocacy, some proponents of Self Advocacy see this as a group-based model that supports a group of individuals to advocate systemically.

One discussion group participant identified five different models of Self Advocacy:

- Independent model where people with intellectual disability set up their own independent advocacy group
- Divisional model where a parent group or service provider establishes a self advocacy group and becomes the sponsoring agency for that group
- Service model where a service such as a group home or Australian Disability Enterprise (business service) has an advocacy group
- Coalition model where a group of advocacy agencies, including self advocacy groups such as People First collaborate together
- People First or Alliance Model where a People First self advocacy group gets together with an individual advocacy agency(ies).

A discussion group participant suggested that Self Advocacy provides a longer term advantage, i.e. through developing the skills and knowledge of people with disability to advocate for their own needs and issues.

Some participants in the consultations for this research project felt that Self Advocacy had limitations.

It is unrealistic to expect that the most vulnerable people with disability will ever be able to advocate for themselves. (Discussion group participant)

We were originally funded as a self advocacy program for people with Intellectual Disability. Over the years people who accessed our agency expressed difficulty when raising issues with their service provider and found that not only did the situation not improve, it often became worse. Individuals were exited from the service as they were seen as trouble makers. They felt that they needed an advocate to assist them to present their issues and to respond on their behalf. This advocacy agency made the transition from Self Advocacy to Individual Advocacy at the direction of our members and committee. (Submission from NDAP-funded advocacy agency)
One Self Advocacy agency present at a discussion group acknowledged that Self Advocacy at an individual level was not appropriate for people who are extremely vulnerable but suggested this model could achieve significant gains at a systemic level. Examples of these achievements included the closure of a residential institution and gaining the right to represent people living in another institutional setting.

Another discussion group participant considered that there was potentially great value in Self Advocacy but probably for people who would not seek support from advocacy agencies.

Other comments in support of Self Advocacy included:

This can increase independence and reduce reliance on advocacy services for individuals and so helps individuals as well as increasing the number of people who are advocating for reform which in turn can lead to systemic change. (Submission from NDAP-funded advocacy agency)

It was suggested that the distinction between Self Advocacy and Individual Advocacy is not always clear. Progression from Individual Advocacy to Self Advocacy was described.

The models of advocacy are not clear cut, especially Individual and Self Advocacy. There may be a combination of these two, with progression from individual to self advocacy over time. (Discussion group participant)

A submission from an advocacy agency suggested that Self Advocacy should be combined with Individual Advocacy in order to be most effective. Under this combined model, people with disability would have a choice of advocating on their own behalf if they had the capacity to do so but would also have ready access to someone to advocate for them if needed.

One Self Advocacy agency representative indicated that, ideally, their organisation would have an alliance with a like-minded Individual Advocacy agency in order to identify systems issues and initiate Systemic Advocacy. This stakeholder is considering establishing a People First organisation to take up systemic issues. One submission expressed concern that there was no longer any Self Advocacy organisation in South Australia.

5.6 Family Advocacy

Family Advocacy places the focus on protecting the human rights and well being of the child with a disability and gives families the knowledge, skills and resources to advocate for their child. (Submission from NDAP-funded advocacy agency)

One interviewee pointed out that Family Advocacy has to exist as a model because young children with disability cannot advocate for themselves.
A discussion group participant described the historical development of advocacy with parent advocacy progressing to a Family Advocacy model. According to one stakeholder, Family Advocacy, as a distinct model, is only practised in South Australia and New South Wales. A systemic approach to family advocacy is used in New South Wales.

One peak body emphasised the need ‘to support carers to have the knowledge, confidence and competence to advocate on behalf of those for whom they care’. This organisation argued that supporting carers in this way would assist disability advocacy services to perform their work.

It is clear that many people in Australia with a disability require assistance from family carers, particularly those with intellectual disabilities and profound or severe physical limitations. . . Carers are often the sole providers of a large amount of advocacy required by those with a disability. (Submission from a peak body)

One Family Advocacy agency told of their work with groups of parents, for example assisting a group to lobby for funding for post-school programs.

A discussion group participant reported that an increasing number of parents receiving advocacy support have mental illnesses, especially depression and anxiety disorders.

5.7 Barriers to Effectiveness

Advocacy agencies identified a wide range of barriers to achieving positive outcomes for people with disability receiving advocacy support. These barriers included:

**Funding and Resources**
- lack of funding and resources in the advocacy sector and in the wider sectors of disability services, housing, education, transport, etc. and rationing of the services that are available
- lack of funding for systemic advocacy work
- lack of funding and services in rural and remote areas
- high and increasing workload
- unpredictable workload

**Attitudes to Disability and Advocacy**
- negative attitudes towards disability, mental illness and advocacy in the community generally and amongst disability service providers and generic services
- poor community and service provider awareness of advocacy and the advocate’s role, e.g. professionals and support workers believing that they can act as effective advocates for the people receiving their services
- service providers fearful of advocacy, resisting involvement of advocates and reluctant to provide advocates with information
• mistrust of volunteer status of citizen advocates

Administration of Advocacy Programs
• models of advocacy limiting flexibility in advocacy response
• NDAP funding allocated by region/geographic location rather than to specific needs (e.g. Deaf people who use Auslan)
• lack of a range of advocacy models in some geographic areas
• the need for national standards and a quality assurance process for advocacy services
• inconsistencies between state and Federal government advocacy funding policies and reporting requirements
• multiple accountabilities, audits and reporting requirements to different funding bodies e.g. ‘advocacy organisations can get audited by three different agencies in one year’
• governance difficulties e.g. challenge of finding the right people for committees of management, particularly in rural areas

Staffing and Recruitment
• difficulty recruiting and retaining suitable staff (in large part due to poor remuneration)
• difficulties recruiting volunteers, particularly police check requirements
• limited skills, consistency and availability of citizen advocates

Professional Development and Networking
• insufficient professional development and training for advocates
• difficulties in networking and lack of time and resources for advocacy agencies to meet together
• limited support for sector development from the NDAP
• insufficient skills in supporting consumers with mental health issues

Knowledge and Information
• lack of knowledge of other advocacy agencies, e.g. for referral, information sharing or collaboration purposes
• consumers’ lack of understanding of their rights and fear of reprisal or being perceived as ‘trouble makers’
• high cost of public awareness campaigns

Legal Barriers
• legislative barriers to advocacy practice, e.g. privacy and confidentiality and consent provisions and conflicts between legislative provisions, e.g. occupational health and safety requirements cited by a disability enterprise as the reason for terminating the employment of person with disability
• legal system can create ‘David and Goliath’ situations where individuals may not have the resources to pursue legal actions against large organisations
• complaints processes may be inadequate, drawn out or selective in response
• attitudes and awareness in the legal professions
• lack of a legal framework for advocacy, i.e. something to legitimise the role of advocates

Cultural Barriers
• cultural barriers including language, cultural concepts of disability, avoidance of service providers due to mistrust, cultural roles and context, e.g. role of carers
• most mainstream disability services not culturally responsive to people from CALD backgrounds who have a disability
• poor disability awareness in ethnic communities and the CALD services sector
• new and emerging migrant and refugee populations
• low levels of English language proficiency and wide range of languages used by CALD consumers

Outreach Barriers
• barriers to advocacy outreach, e.g. distance, restricted access for advocates to facilities/services such as supported accommodation
• insufficient funding to cover geographic areas required and gaps in geographic coverage of advocacy services

Linkage with Service Providers
• consumers involved with multiple service providers and government agencies and difficulty in communicating with all of these parties and getting them together (‘bureaucratic silos’)
• service system resistance and hostility
• advocacy agencies used as a referral point of last resort
• ineffective policies to protect the rights of people with disability, e.g. funding not provided for adequate implementation of policies, or inclusion policies counteracted in practice by exclusions based on occupational health and safety requirements.

Comments regarding barriers to effective advocacy included:
The Privacy Act is a barrier. Staff at one service were told they could not divulge issues of abuse. These protections can actually make people more vulnerable. (Discussion group participant)
Children’s services have refused access to advocacy agencies even where the child is being physically and sexually abused. (Discussion group participant)
There is an amazing level of ignorance about what advocacy is... VET modules for advocacy don't mention the fundamentals of independence and conflict of interest... Someone needs to have a good look at what is being taught to service provider staff. (Discussion group participant)

In individual, family, self and citizen advocacy in particular there is great difficulty responding to complex cases which involve more than one type of disadvantage. For example, a person who is from an indigenous background with multiple disabilities who is in the prison system will require either several advocates with different expertise or one advocate with a very broad training base. (Submission from a disability peak body)

We don't have any authority. We are reliant on the goodwill of service providers for advocacy involvement. Good service providers have policies that allow their consumers to have access to advocacy. If we had power or rights of entry, this would make our job easier but this may not be appropriate for community based services. (Interview with NDAP-funded advocacy agency)

There were barriers for particular groups. For example:

For Aboriginal people, we need to go to them. It has to be face to face. They won't come to you. (Discussion group participant)

The models of advocacy are a barrier, particularly in advocating for people with disability from ethnic communities. We need to do community development in these communities but the funding models mean we can't achieve that. (Discussion group participant)

Advocating against Funding Bodies

Some advocacy agencies spoke of the inherent conflicts that can occur when advocates have to raise issues against a government body that also provides advocacy funding. In many cases, the services that advocacy agencies have to advocate against are funded by the state government that also funds the advocacy agency. It was suggested that responsibility for all advocacy funding should rest with the Federal government.

The view expressed by one discussion group participant that: 'Advocacy is there to keep the bastards honest', reflects a certain degree of antagonism that can be perceived between the interests of service providers and the work of advocates.

'Advocacy' has an adversarial connotation. It is really about trying to get the best outcome for a person with a disability who is struggling with the system. (Interviewee)

Barriers Arising from the 'Six Models of Advocacy' Policy

Overall, there was concern from advocacy agencies that prescriptive demarcation between advocacy models is not reflective of actual practice or of the needs of people with disability.
There is a crossover between models of advocacy when providing Individual Advocacy. There is a risk of being too model-limited. It is about getting an outcome. (Discussion group participant)

The models are artificial. They don’t really make sense. (Discussion group participant)

A range of advocacy models is important. The models are not mutually exclusive. People need access to the suite of models. (Discussion group participants)

One submission from an advocacy agency suggested that the main models of advocacy are systemic, group and individual and the other described models (legal, citizen and self) are actually strategies that are employed under the three main models.

**Managing Complex Issues and Crisis Situations**

A peak body interviewed for this research project described a limited scope of NDAP-funded advocacy agencies to deal with complex, crisis situations that were outside of the traditional issues of accommodation, respite, employment, etc. This organisation reported difficulty in finding advocacy agencies willing to take on an individual advocacy role in cases involving human rights abuses and issues such as chemical restraint, coercive practices, removal of babies from mothers with psychiatric or intellectual disability and sexual assault of women with intellectual disability living in supported accommodation. Legal assistance was also reported to be difficult to access in these situations.

Community legal centres say they don’t deal with people with disabilities because specialist services deal with them. Even disability discrimination legal services say they don’t have the resources or staff training for these cases. (Interviewee)

The conflict between available resources and demand for advocacy support was also an issue.

For Individual Advocacy, we have to prioritise people with the highest need. This means we turn away people who then go on to get into disasters. (Discussion group participant)

**Addressing the Barriers**

Suggestions for addressing the barriers to effective advocacy included:

- education of service providers, governments and the general community about advocacy and the role of advocates
- legislated mandate or formal recognition of the legitimate role of advocacy
- accountability measures to ensure that service providers enable vulnerable people to access independent advocacy and make relevant information available to advocates
- stronger relationship between Individual Advocacy and Systemic Advocacy
- additional funding
effective funding model for the advocacy sector, including appropriate indexation
three-year funding cycle
increased resources for professional development and training
cultural competency training for all service providers and advocacy staff
a cultural dictionary of cultural and religious do’s and don’ts (example already developed by one advocacy agency)
interpreting and translation resources
disability awareness raising with newly arrived migrants and refugees
educating the legal professions about disability and advocacy
changes to the NDAP six models of advocacy policy (refer to section 8 of this report for further discussion and details).

5.8 Contribution to Systemic Change

Systemic issues commonly encountered by advocacy agencies include:
• homelessness and lack of supported accommodation
• lack of supports for people with mental illness
• people with intellectual disability living independently in the community but not eligible for sufficient supports
• limited community support services such as home help.

These issues are amplified by distance in rural and remote areas.

Advocacy agencies described a number of examples where advocacy had resulted in or contributed to systemic change. These examples included:
• improved accessibility of buses, trains and taxis in some states
• accessibility works for public buildings and footpaths
• children with disability now educated in regular schools after many years of strong advocacy
• national focus on removing young people with disability from nursing homes
• creation of the position of Disability Commissioner in the ACT
• devolution of a number of institutions
• Australian contributions to, and signing of, international conventions such as the UN Convention on the Rights of People with Disability
• establishment of services for people with disability in the criminal justice system
• inquiry into the Migration Act following advocacy about discrimination against people with disability
• introduction of the Companion Card for people with disability
advocacy on the practice of seclusion leading to a national committee addressing seclusion practices

- changes in hospital and mental health service protocols resulting from advocacy on individual cases of inappropriate practices affecting people with disability
- protocols developed with some state government services to enhance people’s rights to advocacy
- special coloured leashes planned for hearing dogs to facilitate access on public transport
- introduction of legislation to give tenancy rights to people living in hostels
- increased funding for accommodation support
- contribution to a judicial benchbook
- government funding provided for cultural awareness training of group home staff and values training provided in another setting to address negative attitudes
- changes in police service response to people with disability or mental illness
- increased government awareness of acquired brain injury, including AIHW collection and production of specific data reports on acquired brain injury.

Peak bodies added a long list of further examples, mainly at the national level. FaHCSIA staff also identified outcomes from Systemic Advocacy at state and national levels, including improvements in accessibility to buildings and air travel issues.

There was recognition that all advocacy, formal and informal, leads to systemic change.

In small steps, we all contribute to systemic change. (Discussion group participant)

With the right systems in place for communication between advocates, all of the other advocacy types can provide a valuable contribution to systemic change. Individual, self, citizen and family advocacy can inform the work of systemic advocates by adding personal narratives to policy proposals or suggesting areas of highest need for systemic change. Legal advocates who work in the conciliation and court systems have the ability to bring about change through testing case law or working to achieve successful systemic outcomes through the conciliation of individual disability discrimination complaints. Systemic advocates can raise awareness in the broader community and act as conduits for all of the other forms of advocacy to provide input into political lobbying processes. (Submission from a disability peak body)

Many stakeholders referred to the links between Individual Advocacy and Systemic Advocacy.

Two teams in our agency (Systemic and Individual advocacy teams) meet regularly to decide on systemic issues. Systemic Advocacy may also seek feedback from Individual Advocacy. (Discussion group participant)
Individual advocacy can play a significant role in contributing towards systemic change through providing the evidence base and relevant cases that can be incorporated into any systemic advocacy strategy. (Submission from a NDAP-funded advocacy agency)

Legal Advocacy was considered to have an important role in systemic change.

Legal Advocacy is often extremely effective in contributing to systemic change, both indirectly, through the ripple effect that its successful cases and negotiations have on influencing government departments and service providers to change their policies and procedures, and directly, through targeted policy and law reform/systemic work that Legal Advocacy organisations, such as this advocacy agency do, in response to concerns expressed by constituents as well as matters that become apparent through individual casework. (Submission from a NDAP-funded advocacy agency)

Although one submission suggested that the legal system could limit the systemic outcomes achieved through Legal Advocacy.

Ironically, legal advocates can be limited in the systemic outcomes they achieve by the conciliation and court systems themselves: there is no way for an anti-discrimination body such as the Australian Human Rights Commission to take on systemic-only complaints, so individuals must be found to fight larger battles. If this requires that the case go to court then the individual must have some way of paying costs should they lose. In a community with high rates of welfare dependence this is an untenable way to achieve systemic change. (Submission from a disability peak body)

The contributions of Self Advocacy and Family Advocacy to systemic change were noted. For example, through participation in lobbying and consultation processes, triggering and informing Systemic Advocacy, and making individual representations to government or service providers.

One advocacy agency described how it had integrated Self Advocacy into its Systemic Advocacy functions through the development of consumer reference groups, including a CALD Mental Health Consumers Group, and supported the development of consumer networks such as a Women with Disabilities state branch and an Aboriginal Disability Network.

A key barrier for agencies providing other forms of advocacy as well as Systemic Advocacy was the risk that an advocate could lose the focus on individuals if they got caught up in systemic issues or vice versa. A potential solution is similar to the example above where a resource (team or individual) within the organisation is dedicated to Systemic Advocacy only.

An Individual Advocacy agency felt that this model on its own had no pathway to take systemic issues. Other agencies reported using state or national disability peak bodies.
as an avenue for systemic issues. A peak body representative said that although the peaks were there and funded to undertake Systemic Advocacy, the Individual Advocacy agencies were not bringing their issues to the peaks and there were no mechanisms for this to occur.

Another submission called for stronger links between Systemic Advocacy and Individual Advocacy.

Clearly, good systemic advocacy outcomes are critical to achieving durable outcomes around a given issue. There is a need for systemic advocacy services in each state and territory that can provide evidence based systemic arguments for policy reform and systemic changes to the provision of support and promotion of an inclusive society. To be effective, such services need to have access to expert policy analysis, social research and campaign expertise. There also needs to be a capacity to link leading systemic advocacy agencies with the individual and local systemic action of the agencies whose focus is predominantly individual work. (Submission from a NDAP-funded advocacy agency)

One agency suggested that recent adoption of the Ivo data collection and reporting system (developed by a private company, 1024 and now used by several advocacy agencies) would assist in the identification of systemic advocacy issues.

Conclusions

Individual Advocacy is the most commonly used model of advocacy in the NDAP and appears to be the most effective model for providing short-term advocacy assistance on a wide range of issues to large numbers of consumers.

In practice, Individual Advocacy often incorporates a range of approaches and may use or refer to Self Advocacy, Legal Advocacy, Family Advocacy and sometimes Citizen Advocacy.

Self Advocacy, in various forms, is supported by some stakeholders. Family Advocacy appears to be most important for parents of young children with disability and when providing advocacy for people from other cultural backgrounds where there are close family links and cultural ties.

Although some stakeholders questioned the need for Legal Advocacy, others reported difficulties for people with disability in accessing mainstream legal assistance and identified the need for specialist legal knowledge in addressing legal issues for people with disability. Particular needs were described for people with disability involved in the criminal justice system.

There are conflicting views about the effectiveness of the Citizen Advocacy model. There was strong support from practitioners of this model and a range of concerns raised by others. The concerns were mainly related to the use of volunteers rather than trained staff, long waiting times for advocate:protégé matches and strict adherence to the Citizen Advocacy model and principles limiting flexibility and collaboration.
Stakeholders identified a range of barriers to advocacy models achieving positive outcomes and these barriers include: lack of resources; awareness of and attitudes to disability and advocacy; and inconsistencies between government funding requirements at state/territory and Commonwealth levels.

Systemic Advocacy is the model which most contributes to systemic change. Other models may feed issues into Systemic Advocacy or achieve small systemic changes in their own right. For example, Legal Advocacy may contribute to new legal precedents or legislation.

Systemic change may take several years to achieve and it is often difficult to accurately attribute cause and effect in respect of the role of advocacy in systemic change.

It is apparent that Systemic Advocacy efforts are currently fragmented. This is due in part to: the dispersion of small amounts of funding for Systemic Advocacy across many advocacy organisations; the lack of linkages between advocacy agencies and between advocacy agencies and disability peak bodies; and the absence of a pathway(s) and mechanism(s) for systemic issues to feed through to Systemic Advocacy and ultimately government policy agenda at state/territory and national levels.
6.0 Efficiency of the Advocacy Models

This section reports the findings from the research consultations in response to Research Question 3.

Research Question 3: How efficient are the advocacy models of support?
The research shall:
   a) consider the cost of each model and its benefits to the population target group;
   b) consider the duration and intensity of support required under each model to achieve positive outcomes and outputs for people with disability and public policy; and
   c) critically review each model and advise of the most efficient model(s).

6.1 Comparative Cost:Benefit of Advocacy Models

Analysis of NDAP quarterly report data from funded advocacy agencies and review of the research literature has found no conclusive evidence that one particular model of advocacy has cost:benefit advantages over other models; however, this finding is largely due to the lack of accurate, comparative cost data.

Some interviewees for this research project considered that Individual Advocacy was the most cost-effective of the six models and provided the best value for money in terms of number of people assisted, outcomes and capacity to assist with immediate and crisis needs.

   We see good results and outcomes from Individual Advocacy and these are measurable.  (Interviewee)

Citizen Advocacy agencies suggested that Citizen Advocacy was a cost-effective model due to the use of volunteers; however, several interviewees considered that Citizen Advocacy was an expensive model.  Costs of between $2,500 and $4,500 per consumer per annum were cited.  One concern appeared to be the limited number of matches that a Citizen Advocacy agency can make.

   I don’t believe that Citizen Advocacy is something the Department should be funding as part of this program. . . It is definitely a support but probably not ‘advocacy’.  It is a very expensive model but we don’t get a lot of results and outcomes.  It is hard to know what would happen if it wasn’t there.  (Interviewee)

One interviewee recognised that Citizen Advocacy would be cost intensive for the initial matching process but wondered if the model would be more cost-effective over the longer term due to the use of volunteers.

Legal Advocacy was also described as a potentially expensive model, particularly where legal issues extend over a long period of time.  Some stakeholders suggested that this form of advocacy should be funded and/or administered through Attorney-General’s departments.

Some stakeholders doubted the cost:benefit of Self Advocacy when compared to Individual Advocacy.
Family Advocacy was considered to be a cost-effective approach with long-term benefits: ‘Families do it over a lifetime’.

There were no consistent views from advocacy agencies regarding the comparative cost:benefit of the six models of advocacy. Some agencies identified the wider benefits achievable through Systemic Advocacy.

Systemic Advocacy has the advantage of potentially bringing benefit to much larger numbers of people for the time spent as well as serving to reduce clients repeatedly presenting for Individual Advocacy with the same or similar issues. (Submission from a NDAP-funded advocacy agency)

One agency suggested that it was more useful to look at the cost:benefit of various strategies than distinct models.

It is probably less useful to make a comparison between the various models on an either or basis but to look at how a variety of strategies contributes something worthwhile to meeting both the needs for intensity of application and duration of positive outcomes for an individual. Perhaps there needs to be more of an interface between the different strategies or different streams within the program that meet different needs. (Submission from a NDAP-funded advocacy agency)

Another stakeholder felt that the achievements of advocacy agencies were more likely to result from the personnel of the agency than the model of advocacy used.

It gets back to the people leading advocacy having the leadership ability to effect change. The contribution is more a result of individuals than a specific model of advocacy. (Interviewee)

The advocacy agencies participating in this research project have generally indicated that they are operating with insufficient resources to fully meet demand.

The government is getting very good bang for the buck from advocacy. (Discussion group participant)

There was general agreement that operating costs for advocacy agencies had increased markedly over the past few years, including costs of leasing premises, staffing costs and petrol and travel costs.

6.2 Suggestions for Improving the Efficiency of Advocacy

Stakeholders’ suggestions for improving the efficiency of advocacy resources included:

- networking and sharing information, policies and ideas
- sharing information through a website and/or newsletters
- collaborating on and sharing training programs
- co-location and shared administration and training opportunities
• reviewing some administrative/funding aspects e.g. purchase versus lease of a car
• group purchasing arrangements for insurance and auditing services
• using technology such as teleconferencing and other information technology, particularly for advocacy agencies in rural areas
• a three year funding cycle to improve staff retention and assist in negotiating more favourable arrangements such as office leases
• funding allocated on a client/issue basis with a better auditing process
• for systemic issues, using existing infrastructure to engage a position(s) to conduct Systemic Advocacy
• pooling resources for Systemic Advocacy, i.e. currently several advocacy agencies in one state each receive a small amount of funding for systemic advocacy, but do not work together
• a standard consumer database
• standard advocacy guidelines
• simplifying and streamlining reporting arrangements
• use of pro-bono support where possible e.g. for legal services.

One interviewee suggested that there should be fewer but larger advocacy organisations with greater flexibility in how they use their resources. This view was supported by a peak body that considered some advocacy agencies were too small to cover infrastructure costs. Conversely, another interviewee considered that smaller services may be more responsive and willing to meet immediate needs. This interviewee stressed the importance of having a local presence.

Participants in two of the discussion groups claimed that the Australian Taxation Office definition of a charitable organisation restricted the ability of advocacy agencies to attract philanthropic funding. Another advocacy agency described fundraising difficulties even with charitable status.

Our ability to attract private donations is very restricted, even with charitable status. We need the resources to go out and seek this funding. We are coming up against established disability fundraisers such as organisations for people who are blind or have cerebral palsy. Advocacy is a difficult concept to fundraise for. (Interview with NDAP-funded advocacy agency)

Conclusions
An advocacy model that focuses primarily on Individual Advocacy but has the flexibility to use or refer to other approaches (e.g. Self Advocacy, Legal Advocacy or Family Advocacy) as needed by an individual from time to time, appears to offer the highest cost:benefit on a total population basis, although this cannot be confirmed due to the lack of accurate and comparable cost and outcome data.
A way of improving the cost:benefit of advocacy is to develop a mechanism(s) and pathway(s) for Individual Advocacy issues, particularly those issues that cannot be readily resolved or that occur repeatedly, to feed through Systemic Advocacy to state/territory or Commonwealth government policy agenda.

Increased collaboration and resource sharing between advocacy agencies would also provide a cost:benefit advantage.

A three year funding cycle could assist agencies with issues such as forward planning, staff retention and leasing of premises.
7.0 Extent to which the Advocacy Models Collaborate and Feed into Public Policy

The findings in respect of Research Question 4 are discussed in this section.

Research Question 4: To what extent do the different models collaborate and feed into public policy?

In considering this, the research shall have regard to:

a) the effectiveness of the different models in feeding into public policy;

b) the extent and effectiveness of the models in collaborating and complementing each other in practice; and

c) the extent to which the specialist services share their knowledge to support generic services.

7.1 Advocacy Input to Public Policy

Advocacy agencies may have direct or indirect input to public policy.

Advocacy agencies regularly sit on advisory groups, boards and state government committees and act as a support person for consumers on committees. (Discussion group participant)

Activities reported by discussion group participants included:

- participating in Ministerial Advisory Councils
- attending consultation forums
- preparing written submissions, sometimes in collaboration with other advocacy organisations
- appearing in person at select committee hearings and inquiries
- writing letters to government ministers
- providing case studies to assist systemic advocacy agencies
- assisting individuals with disability and their families to tell their stories to government ministers.

One participant noted that they had to be selective about these activities due to time and resource constraints.

One advocacy agency described the example of a state government department funding an advocacy agency and carers’ network to assist with a consumer satisfaction survey. Three consumers and three carers interviewed consumers at a number of sites. This reportedly gave consumers a sense of ownership and focussed attention on consumers’ experiences of services rather than just satisfaction. This approach was apparently so successful that it is now being considered for national use. The advocacy agency suggested that this was a good example of research and Systemic Advocacy influencing public policy.
In another example, the Young People in Nursing Homes campaign was co-funded by Commonwealth and state/territory governments. A dedicated project worker was employed and interested agencies were involved. It was suggested that the single focus of this campaign and the use of good lobbying skills were important factors in the campaign’s success.

Stakeholders described the ways in which different models of advocacy (primarily Systemic, Individual and Legal Advocacy) feed into public policy. For example:

Individual advocacy is a key part of public policy change if it feeds information about practical problems that people with disability face into the system. (Submission from NDAP-funded advocacy agency)

Major submissions and lobbying campaigns are the mainstay of effective influencing of public policy and are the main work of Systemic Advocacy organisations. They organise input from and collaboration with all the other advocacy organisations to achieve a more effective level of influence on public policy. (Submission from NDAP-funded advocacy agency)

Legal Advocacy is often extremely effective in feeding into public policy, both indirectly, through the ripple effect that its successful cases and negotiations have on influencing government departments and service providers to change their policies and procedures, and directly, through targeted policy and law reform/systemic work that Legal Advocacy organisations, such as this advocacy agency do, in response to concerns expressed by constituents as well as matters that become apparent through individual casework. (Submission from NDAP-funded advocacy agency)

When asked how the linkages between advocacy and public policy could be improved, advocacy agencies suggested:

- targeted campaigns with champions and strong leaders
- a cohesive, unified approach
- ‘real consultation processes that view individuals with a disability as the primary stakeholder’
- employment of people with disability in government policy development areas
- appropriate recognition and funding of advocacy through enforceable legislation
- increased public awareness of advocacy
- increased links and collaboration between Individual Advocacy and Systemic Advocacy agencies
- more interaction between advocacy organisations and government/politicians
- development by bureaucracies of a direct link between the issues highlighted in advocacy reports and policy development
education of services and government authorities about disability legislation and a human rights framework
formalising structures of communication and reporting
creating regular, scheduled meetings and reporting mechanisms
increasing the capacity of government and non-government agencies to be more responsive to advocacy feedback and input
establishing an annual National Advocacy Forum as a means of consulting widely and providing feedback about implementation of changes
running workshops across Australia to collect information on what people with disability or carers identify as their top issues and using this evidence to feed into public policy processes.

The problem is not so much with public policy but with the implementation of policy. (Discussion group participant)

The importance of effective linkages between Individual Advocacy and Systemic Advocacy was also emphasised.

While systemic advocacy by definition should be good at feeding information into public policy it also needs the knowledge base provided by individual advocacy to have the maximum effect. ( Submission from NDAP-funded advocacy agency)

One submission from an advocacy agency noted that there are three main national forums that provide a voice for people with disability in the formation of public policy:

- the National Disability Advisory Committee (NDAC) – (Author’s note: The National People with Disabilities and Carer Council has replaced the NDAC)
- Australian Federation of Disability Organisations (AFDO)
- Disability Advocacy Network of Australia (DANA).

It is our view that FaHCSIA needs to work with all three groups in the public policy process around matters that affect people with disability and their families. (Submission from NDAP-funded advocacy agency)

This submission suggested there was some confusion about the relationship between AFDO and advocacy organisations funded under the NDAP or by state and territory governments. The submission said that the formation of DANA as a peak advocacy voice for independent disability advocacy organisations had brought this issue into focus. Some advocacy agencies reported difficulties in gaining AFDO membership due to a requirement that the organisation be managed by people with disability but the exact nature and extent of these difficulties are unclear.
7.2 Collaboration and Networks

The importance of collaboration was recognised by the advocacy agencies participating in this research.

Referrals and collaboration are extremely important as they enable advocates to use the various relevant models of advocacy to work together to achieve best possible outcomes for individual clients.

(Submission from NDAP-funded advocacy agency)

Advocacy agencies and other stakeholders acknowledged that collaboration and leadership have been problematic in this sector.

. . . one of the key shortcomings is the poor linkages between individual advocacy and systemic advocacy. While some of this may be based on perceived ideological differences between the models it is important that both models work together. If services are unable to establish such collaborative relationships themselves then perhaps funding bodies need to find ways to actively encourage such collaboration or even mandate such collaboration through funding contracts. While individual advocacy organisations have probably been more proactive in seeking collaboration with systemic advocacy groups it appears the opposite is not the case.

(Submission from NDAP-funded advocacy agency)

A great number of the advocacy organisations do not liaise with disability peak organisations for reasons which are not clear.

(Submission from a disability peak body)

Stakeholders suggested a number of reasons for poor linkages and inadequate networking, including high staff turnover, high workloads, lack of resources and protectiveness.

The models of advocacy themselves work well as they are for very good reasons. Each advocacy model addresses the specific needs of a group of people with disability, or of disability advocacy issues as a whole. However, the way advocacy types work together to develop and share expertise and talk about ongoing issues does need to change. There are some clear divides in the advocacy sector which could be addressed through networking opportunities and resources to develop better internal and external relationship processes. These include gaps between:

- professional and informal advocates;
- different advocacy types from different agencies;
- different advocacy types within the one agency.

The issues around why these gaps occur are complex. For example, high staff turnover and workloads mean that it may be difficult for organisations to maintain networks. A lack of resources for establishing
relationships between formal and informal advocates may be a more prevalent issue than a lack of will to do so. (Submission from a disability peak body)

Some disability organisations are very territorial. They have fought for a long time to exist. The notion of collaboration is seen as a threat to their autonomy and existence. There are vested interests and boundaries – this weakens the sector. (Interviewee)

A number of state networks of advocacy agencies exist. The Victorian Disability Advocacy Network (VDAN), for example, holds four one-day meetings per year. There is also a rural advocacy network in Victoria.

One NDAP-funded advocacy agency said that membership of the state advocacy network provided ‘a vehicle for cooperation and coordination of advocacy effort around key issues as well as providing a forum for sector development and professional development for advocates’.

A new national body, the Disability Advocacy Network of Australia (DANA) has recently been provided with funding by FaHCSIA. One of the aims of DANA is to create mechanisms for linking advocacy agencies that want to work with others to address special issues.

Several advocacy agencies described collaborations with other advocacy agencies and models.

This advocacy agency often works in conjunction with other agencies and advocates on individual cases. For example, we will ask a rural or regional advocate, or a metropolitan one, to meet with a client on our behalf, or sometimes also with us, to seek information or provide advice or support. The reverse of this also often happens. This is often a far better use of this advocacy agency’s resources than us driving to far reaches of the state a number of times, when it may only be necessary for us to do so once in the process of a case, for a court or tribunal hearing. (Submission from NDAP-funded advocacy agency)

One interviewee told how Systemic Advocacy agencies in their state banded together to run campaigns, pool resources and present to government as a united front. Another described how a Citizen Advocacy agency was tending to look more widely in terms of external referral and finding ways to complement their service. This meant the agency was now actually providing a larger service.

Some advocacy agencies were involved in wider networks with generic agencies.

In the South-West, we have some big network groups involving hundreds of different agencies. We get together and talk about issues. (Discussion group participant)

In other jurisdictions, there had been less success.
We only all get together when a specific meeting is called, usually by government. We tried to have a network for quite a long time but this didn’t work. (Discussion group participant)

One submission emphasised the importance of the advice and information that advocacy agencies provide to individuals and other services.

There needs to be more acknowledgement that advocacy resources are used to provide secondary consultation to other services, advocacy groups and people with a disability and their families. This is an important role as, like self and family advocacy, it increases the number of empowered groups who have an interest in advocating on behalf of and with people with a disability. For example advocacy groups provide advice and information to many services which are part of the community sector such as housing information services. (Submission from NDAP-funded advocacy agency)

Advocacy agencies were keen to meet on a regular basis (e.g. quarterly) to identify common systemic issues. One discussion group suggested that funding should be provided for someone to organise these meetings and drive the process.

Stakeholder suggestions for improving collaboration between models of advocacy included:

- appropriate funding of a national advocacy body and state advocacy networks
- regular meetings with other advocacy agencies
- resources for networking opportunities and conferences
- having individual and systemic advocacy programs run by the same organisations
- more sharing of information between agencies
- increased professional development and networking to encourage collaboration and increased resources to enable all advocacy agencies to participate
- attending and presenting at advocacy conferences
- forming cooperative relationships with other advocacy programs including specific advocacy groups i.e., mental health, indigenous/ethnic specific, etc.
- finding and discussing common issues and practice principles within advocacy community
- encouraging respect towards all legitimate advocacy practice including respect for the specialisation that each model offers and brings.

Advocacy resource units were also suggested as a means of strengthening advocacy and improving collaboration.

Advocacy resource units . . . are an excellent way of strengthening advocacy and improving collaboration. They provide an opportunity to work together in systemic issues including bringing together agencies
who provide differing models. They improve the referral process between advocacy agencies. They provide training opportunities so that the way the models are used is strengthened by better understandings of legislation and policy and the practical advocacy strategies that can be used under each model. These units . . . have been instrumental in bringing advocacy groups together across the country and if more statewide units were available this would further enhance and improve coordination and advocacy effort. (Submission from NDAP-funded advocacy agency)

Another submission called for the establishment of an adequately funded Systemic Advocacy agency in each state/territory ‘with a mandate to consult and involve all other advocacy agencies’.

One advocacy agency suggested that collaboration was beginning to improve in a context of some resistance.

We think there is a culture of collaboration starting to develop across the sector although it is very slow and there still remains a lot of caution on the part of smaller services to become involved in such collaborations. Some of this caution appears to be related to perceived ideological differences about advocating for people with a disability along with some advocacy services being concerned about the “professionalisation” of the sector. Our view is that increasing the skills of advocates and managers of advocacy services is vital to the improvement of the sector and increasing the professionalisation of advocates and managers is a good thing in the long run. (Submission from NDAP-funded advocacy agency)

Differences in the state/territory and Commonwealth funding programs for disability advocacy also affect linkage and collaboration. For instance, there are about forty advocacy agencies that are funded by state/territory governments but not by the NDAP and there are few formal linkages between these programs at a local level.

Conclusions

Systemic Advocacy is the model that has the greatest input to public policy. Legal Advocacy has a role in legislative change and other legal changes such as precedent law.

Many advocacy agencies are involved in consultation and consumer participation processes that inform public policy, for example through membership of advisory committees and responding to calls for submissions.

As stated in Section 5.0 of this report, advocacy input to public policy could be enhanced by better linkages between Individual Advocacy and Systemic Advocacy and pathways for systemic issues to feed through to government policy.

Although advocacy agencies recognise the need for and benefits of collaboration and networks, the level and effectiveness of collaboration is inconsistent.
8.0 How the Models of Advocacy and the NDAP Program can be Developed and Strengthened to Meet Future Needs

This section presents the research findings relating to Research Question 2. Suggestions regarding potential measures or indicators of success for the NDAP are also discussed in sub-section 8.3.

Research Question 2: How appropriate are the six advocacy models?  
*The research shall consider:*

a) whether the models are relevant to the present and future needs of Australians with disability; and  
b) any modifications that need to be made to the models to meet current and future needs.

8.1 Meeting Present and Future Needs

**Appropriateness of the Models of Advocacy**

Advocacy agencies generally considered that the current models of advocacy that they use are appropriate. There were concerns about the lack of flexibility in the current NDAP funding agreements which require agencies to provide specific proportions of advocacy models. Other stakeholders also had concerns about the focus on models of advocacy.

The current models work well if people have a choice of model.  
(Discussion group participant)

It doesn’t work well with each agency relating to the Department and being funded to provide only one model of advocacy. (Discussion group participant)

There should be more focus on the outcomes and aims of advocacy rather than on the models – the models are driving the thinking rather than the outcomes. (Interviewee)

This view was highlighted for people with disability from culturally and linguistically diverse backgrounds.

The current models do not reflect the comprehensive and flexibly inclusive approaches found necessary in actual practice to achieve quality outcomes for CALD people with disabilities.

**Diversity of Advocacy Models**

There was support for the continued availability of specialist advocacy services, for example, those with specific expertise in multicultural or Indigenous issues, or a specific disability type, such as mental health or acquired brain injury. These agencies should not work in isolation but should link with other agencies as needed.

There needs to be a recognition that advocacy in mental health is a speciality where to be effective the advocate needs to have an intimate
knowledge of the Mental Health Act, Chief Psychiatrists guidelines, clinical and non-clinical standards of practice, health and other complaints legislation and processes, government policy, etc. 
(Submission from NDAP-funded advocacy agency)

**Resources and Service Gaps**
Some stakeholders expressed concerns about the adequacy of the current NDAP and models of advocacy and service gaps. The main concerns were:

- an uneven mix of advocacy services across the country
- lack of advocacy services for people with mental illness and people who are Deaf
- lack of legal advocacy support for people with mental illness and people with acquired brain injury in the criminal justice system.

Several submissions argued that limited funding and resources reduced the ability of advocacy agencies to meet the needs of people with disability.

**Aims, Outcomes and Identity**
One peak body identified concerns that advocacy agencies may be ‘too insular and protective of what they do’ and lack clear direction, aims and nationally consistent guidelines.

Other stakeholders described the benefits of the NDAP.

> Advocacy creates a bond. People with disability know that there is someone there for them if they need it. (Interviewee)

One interviewee reported that advocacy had been ‘really integral’ to successful outcomes for people with disability in situations that had arisen relating to employment in that state: ‘The situation was handled so well by the individual advocate.’

One submission noted that there is no generic label to identify advocacy organisations to consumers who require advocacy assistance. In another sector, FaHCSIA-funded business services that employ people with disability are now known nationally as Australian Disability Enterprises and there is common resource material and information that these agencies can use for community information and other purposes. A similar common identifier may be appropriate for advocacy agencies.

**Quality and Standards**
A peak body was concerned about the variable quality of advocacy service provision and about one situation in particular where the organisation felt that inappropriate and costly action had been taken by a legal advocacy agency against service providers and a government department.

Another peak body considered that the Disability Services Standards were inappropriate for advocacy and said their organisation had resorted to using the old CHASP standards for their systemic advocacy work and more recently moved to Quality Improvement Council standards.
8.2 Suggested Modifications to the Advocacy Models and the NDAP

Aims and Priorities

One of the FaHCSIA staff interviewed for this research identified the need for the NDAP to have a clear ‘program logic’ in what it aims to achieve. It was suggested that the advocacy sector is underdeveloped and needs to develop and focus its purpose and objectives. The primary focus should be to assist people with disability and address the barriers that impact on their daily lives.

A discussion group stressed that the focus of a national advocacy program should be on the most vulnerable of people with a disability.

The program needs a focus that is clearly on the most vulnerable people with disability. We will never be able to meet the needs of all people with disability or all people who could benefit from advocacy support. The program needs to be clear about the target group. For example, there is a growing group of people with mental illness who are particularly vulnerable, people who are institutionalised and have very complex issues. (Discussion group participant)

The need to be clear about what advocacy is and to base advocacy on strong principles was also highlighted.

Advocacy has to look, sound and act very differently from human services, for example, we can’t use the word ‘clients’, we need to address people as people. We need sound, strong values and principles to lead advocacy and a clear definition of what we mean by advocacy. (Discussion group participant)

We need acceptance that all models of advocacy are necessary and a common understanding of how the different models work and what the principles are. We need agreement on common principles of advocacy that we all share. (Discussion group participant)

Continuing independence of advocacy was also supported.

Diversity in Advocacy Models

Advocacy agencies and other stakeholders supported continued diversity in the range of advocacy models available.

It is critical that there are a variety of strategies and approaches to meet individual needs. (Discussion group participant)

It is important for NDAP to recognise the diversity of philosophies and models – it should not be a ‘one size fits all’ approach. (Discussion group participant)

All models are useful at some time or another, even for the same person and the same outcome need. One model may be more effective at different times in the advocacy process. For example, family advocacy
could be used first for an issue, then individual advocacy, then systemic advocacy after all the other types of advocacy have been used and exhausted. (Submission from a peak body)

Some Citizen Advocacy representatives supported continuation of a specialist approach.

Citizen Advocacy will continue to support specialist models, not a one-stop generic model. We will be clear about what we are doing and why. We will do a particular thing and do it very well. (Discussion group participant)

Specialisation was also supported in relation to specific types of disability, for example, psychiatric disability, sensory disabilities and acquired brain injury.

There are complexities in providing advocacy for people with psychiatric disability. For example, there is specific legislation in this area. There is a need for specialisation in this area, advocates who understand the mental health system and services. People who have worked with people who have intellectual disability may not be comfortable working with people who have mental illness. (Interview with NDAP-funded advocacy agency)

One advocacy agency recommended a regional approach, ensuring that people with disability in each geographic region have access to generalist Independent Advocacy, specialist advocacy services and Systemic Advocacy.

When considering a model or structure for delivery of independent advocacy support across the nation, it is going to be important to explore how each region is going to be served by the NDAP funding and what contribution each model can make to meet the objectives of the program. Key elements for consideration include:

- At least one statewide systemic advocacy program in each state/territory
- Access to generalist independent individual advocacy services in each region with resourcing linked to population size and size of area covered.
- Access to specialist advocacy services (legal, issue specific, etc) that supplement and support regional advocacy effort but do not duplicate services for specific populations.
- Consideration for a program of voluntary advocacy support that complements existing regional advocacy services – this may need to be seen as a separate program stream within the program. (Submission from a NDAP-funded advocacy agency)

**Individual Advocacy and Systemic Advocacy as the Primary Models**

When stakeholders were asked if there was a particular combination of models of advocacy that achieves more positive outcomes than either model used alone, the
The combination of individual advocacy and systemic advocacy is probably the most effective for people with disability. People’s individual problems are addressed in a timely fashion but when common problems arise systemic advocacy (based on the practice evidence of individual advocacy) can have better input into the policy process. (Submission from a NDAP-funded advocacy agency)

It is our view that there are two basic forms or models of advocacy that are relevant to the National Disability Advocacy Program – individual advocacy and systemic advocacy. Of the types or models of advocacy listed, they fit into one or other of these two basic models. . . It is better to have a more simplified model of individual advocacy that allows for a variety of approaches than to prescriptively define each approach as a separate service/model or funding stream. (Submission from a NDAP-funded advocacy agency)

Get rid of the models. Keep one or two, for example, Individual Advocacy and Systemic Advocacy, but Systemic Advocacy should be separate from Individual Advocacy. There are too many definitions and models. This has caused mass confusion and has set up barriers in agencies’ guidelines and criteria. The program needs to be reframed from the top in terms of a human rights model. The United Nations Convention spells this out for you. The framework is there. (Interviewee)

One submission suggested that Systemic Advocacy ‘is more credible when it is mandated through the individuals that make up an organisation’s constituency and others called for better linkages between Individual Advocacy and Systemic Advocacy.

There will always be an important role for agencies which concentrate primarily on systemic advocacy. However these agencies need to better collaborate with the more generic/individual advocacy services to underpin the evidence for their systemic advocacy and support generic advocacy agencies in their more small scale systemic advocacy efforts.

We believe that individual advocacy is most effective where it is supported by systemic advocacy processes which implement change that will benefit an entire demographic. This coupling of individual and systemic advocacy may be carried out by one service or across multiple services. (Submission from a peak body)

Some stakeholders cautioned against combining Individual Advocacy and Systemic Advocacy within an advocacy agency. This was mainly due to the potential for Individual Advocacy needs to draw resources away from systemic work.

It is important to keep programs separate to avoid tensions in relation to how resources are spent. It is difficult to determine the resources needed
to complete a systems advocacy response or an individual advocacy response. If both programs were undertaken by the one agency one program may be disadvantaged. This model had been trialled in Brisbane and was found to be a poor use of existing resources. (Submission from a NDAP-funded advocacy agency)

Other combinations of advocacy models suggested by stakeholders included:

- Individual, Self and Family Advocacy combined with Systemic Advocacy
- Systemic Advocacy and Self Advocacy
- Citizen Advocacy and Individual Advocacy within the one agency
- Individual, Self and Legal Advocacy combined with Systemic Advocacy at state and national levels.

One submission cautioned against combining Legal Advocacy with other approaches. This submission also advised against any further increase in the use of litigation as a means of resolving issues in the disability sector and recommended more conciliatory approaches.

One submission from a NDAP-funded advocacy agency recommended that the model of advocacy needed to be broadened so that Individual Advocacy and Systemic Advocacy:

- include engagement with families/carers and cultural communities (particularly for CALD people with disability)
- enhance self-advocacy as a core component
- shift from a reactive to a proactive focus
- place emphasis on substantive quality of life outcomes that provided substantive equality for CALD people with disability.

Identifying and Addressing Systemic Issues

Stakeholders highlighted the importance of adequate resources for Systemic Advocacy.

Government needs a better understanding of resourcing preventative, systemic advocacy rather than picking up the pieces afterwards. (Discussion group participant)

Quarantined resources, appropriate skills set and a mechanism for identifying and progressing systemic issues were important suggestions coming from a range of stakeholders.

It needs an independent person to pursue systemic advocacy issues. Setting up a separate agency for systemic advocacy may not be the most efficient option. You don’t need an office, just the individual. (Discussion group participant)

We need to try and quarantine the Systemic Advocacy role so a person with the right skill set can look at issues, analyse information, write
submissions, etc. without competing demand from client issues.

(Interview with NDAP-funded advocacy agency)

At the state/territory level, one interviewee described an environment where agencies have to close their books to Individual Advocacy at times, with no resources available for Systemic Advocacy (despite small proportions such as five per cent of advocacy agency funding allocations assigned for Systemic Advocacy). This interviewee suggested that, particularly in smaller states, statewide Systemic Advocacy funding could be allocated to one agency with this dedicated resource isolated from use for other forms of advocacy. Another interviewee supported a similar approach:

Systemic Advocacy needs to be more focussed on a strong agency or body that is going to be able to push the issues. An agency with strong networks and research behind them. Spreading small amounts of funding for Systems Advocacy over several agencies is not effective.

(Interviewee)

One rural advocacy agency said they had tried referring systemic issues to a statewide advocacy service informally but this had not been effective and they were now developing a formal memorandum of understanding.

At the national level, one suggestion was a national forum to consider systemic advocacy issues. A more detailed proposal from discussion group participants was a formalised structure to identify, prioritise and take action on systemic issues. This structure would be government driven, with terms of reference, a specific agenda and the parties called to the table on a regular basis.

An interviewee also suggested a formal structure such as a reference or advisory group for bringing systemic issues including key blocks and barriers encountered by people with disability, to be taken up with government. Such a structured approach would give the advocacy sector a clear pathway and ability to inform government of systemic issues and the issues would be tabled and on record along with supporting evidence.

Some FaHCSIA state/territory officers suggested that they are ideally placed to have a role in identifying systemic issues coming through in the quarterly (now six-monthly) reports from NDAP-funded advocacy agencies. This could complement a statewide systemic advocacy agency to identify state and national systemic issues and feed these into a national systemic issues agenda.

Some Self Advocacy and Citizen Advocacy representatives considered that Systemic Advocacy activities would go beyond their core purpose but felt that they could still meet with other agencies to discuss systemic issues.

Disability peak bodies suggested that their organisations should be included in Systemic Advocacy initiatives.

The establishment of 8 eight peak advocacy agencies based on disability types/ population groups (Intellectual, Physical, Psychiatric, Acquired Brain Injury, Blind, Deaf, NESB and ATSI) to undertake systemic advocacy (as well as individual advocacy; community education;
research and information gathering; and advocacy development) These agencies could be the existing National Disability Peak organisations which are already in place. (Submission from a disability peak body)

FaHCSIA should be funding peak organisations to do systemic advocacy. (Interviewee)

**Collaboration and Networking Opportunities**

Stakeholders supported stronger collaboration and information sharing between advocacy agencies as part of any future advocacy system. (Refer to earlier discussion on this issue in Section 7.2.)

**Addressing Service Gaps**

Stakeholders identified some service gaps in Australian advocacy services. These gaps included an absence of some types of advocacy in some geographic regions or in a state/territory jurisdiction, for example, no NDAP-funded systemic advocacy agency in Tasmania. Concern was also raised about people with disability who are unaware of and/or unable to initiate contact with an advocacy agency.

Those who are most in need of advocacy are least able to access it. We need a formal strategy to deal with this. What do we do to provide advocacy for these people? For example, people who are severely disabled and can’t speak for themselves and can’t contact an advocacy agency. There needs to be a mandate for this type of advocacy. (Interviewee)

Suggestions to identify and address these gaps included:

- mapping all Commonwealth and state/territory government-funded advocacy services available by type and geographic region (such an exercise is already underway)
- considering initiatives similar to the Community Visitors’ scheme used in the aged care sector to provide access to advocacy for people with disability who cannot self-refer to advocacy agencies and have no family members able to advocate on their behalf
- introducing a ‘non-instructed advocacy’ model similar to that used in the United Kingdom which provides advocacy support for people who are unable to give instructions.

**Funding**

In terms of funding advocacy agencies, the most common request was for more resources and funding.

In themselves the models are appropriate but the funding and resourcing needs to improve if the needs of people with a disability are to be able to compete equally with those of other players in the public policy sphere. (Submission from NDAP-funded advocacy agency)
Two submissions recommended a single national advocacy program administered by the Commonwealth Government with the states and territories continuing to contribute funding. One interviewee suggested that a percentage of the budget of each government department (e.g. education, health, justice, transport, etc.) should contribute to advocacy funding.

Several advocacy agencies said that a three-year funding cycle would improve planning and resource allocation and help with staff retention.

One suggestion from discussion group participants was population-based funding.

Funding should match the population or level of disability in a community. (Discussion group participant)

More flexibility in funding conditions was also requested.

There is a danger in being too prescriptive in how funding can be used, for example, what the advocacy agency can do with the funding. We need the flexibility to do cost-effective activities such as consumer forums instead of individual information provision. This doesn’t fit into an Individual Advocacy model. Community development may be more effective in achieving outcomes for the individual and increasing community capacity. (Discussion group participant)

FaHCSIA asks advocacy agencies to nominate the percentages of advocacy models used. This is a bit artificial, too rigid and does not reflect what is actually done. Pinning them down to a specific percentage of advocacy types is not helpful. We need a funding agreement that better reflects reality and required outcomes. (Interviewee)

One submission suggested a funding formula to ensure a minimum level of systemic advocacy.

If there was a formula that with the appointment of for example 6 individual advocates there is also funding to appoint a systemic advocate who attends to the systemic issues arising out of individual and group advocacy. (Submission from NDAP-funded advocacy agency)

Another point was the need for funding to be free from conflict of interest. One submission recommended that advocacy funding be separated from the arm of government that funds and administers other disability services. Another suggested that agencies providing other disability services, such as respite and residential support, should not be funded to undertake advocacy as this would create a conflict of interest.

One stakeholder suggested that the NDAP funding needed significant revision.

NDAP needs a funding system that actually identifies what a service does and gives appropriate remuneration for that service – a more appropriate distribution of NDAP funding, for example, what can the service provide, to how many and where can it go in the future. The traditional funding
model has gone on too long and has now got to the stage where it’s not fair.’ (Interviewee)

One interviewee suggested that the NDAP should reserve $10-20,000 per annum for one-off emergency advocacy, e.g. to provide advocacy support in the event of closure of employment services.

**Reporting Requirements**

The reporting requirements of government funders attracted considerable comment from advocacy agencies. There were concerns about:

- having to meet multiple reporting requirements from different funders
- the costs of producing reportable data
- repeated changes in reporting requirements
- the value and use of reported information
- inconsistent feedback from NDAP quarterly report data across states and territories.

Common reporting requirements across state/territory and federal governments were suggested, as well as one set of advocacy standards.

. . . standards would allow for greater consistency across jurisdictions and a clearer understanding among clients with disability about what an advocacy service should provide. (Submission from a disability peak body)

There was positive feedback about the new NDAP reporting process to FaHCSIA, although one submission noted that the data supplied by advocacy agencies to FaHCSIA does not recognise the information, advice and referral provided to people with disability and their families.

This is a very minimalist form of self and family advocacy but we never record it as such or put these people “on the books” as it is really just provision of information, advice and referral and may only be one long phone call. We do record it as information and advice. (submission from NDAP-funded advocacy agency)

**Training**

With the exception of lawyers working as legal advocates, there are few, if any, standards about what qualifies one to do advocacy work, how those skills are developed and what good advocacy outcomes should mean. (Submission from a disability peak body)

A number of suggestions were made regarding training for the advocacy sector:

- a national training package on advocacy at the Certificate III and IV levels (at present there is only a brief module)
- training in legislative mechanisms and appeals mechanisms
- training packages on self advocacy for advocates and consumers
- annual governance training for boards of management of advocacy agencies
- nationally consistent advocacy training with local adaptation to recognise state/territory differences
- use of a Disability Advocacy Resource Unit at state level to provide regular low-cost training tailored to professional disability advocates of all types.

Both paid and informal advocates should have access to regular and appropriate training, and to resources and the funds to maintain them. Training for advocates would need to cover a wide range of areas directly and indirectly related to the work of an advocate, such as legal issues, writing funding submissions, running campaigns and conflict resolution. Training for some advocates – such as self advocates and family advocates – would need to be specially developed and targeted. (Submission from a disability peak body)

**Quality and Practice Standards**

One submission from an advocacy agency recommended a system of accreditation for all advocacy organisations to improve the overall performance of the sector. Other submissions supported the introduction of specific standards for NDAP-funded advocacy agencies and for consistent practice standards across advocacy agencies.

External quality audits may pick up issues. . . Quality Assurance has been really helpful in employment services and hopefully the same will happen in NDAP services. (Interviewee)

Several advocacy agencies, mainly in Victoria, have formed a Quality Improvement Partnership with the aim of improving quality standards and sharing policies and procedures. The process will include peer assessment and provide opportunities for the board of management chairpersons to meet.

**Other Suggestions**

Other key suggestions from stakeholders included:

- a central referral site/website or advocacy directory with details of all advocacy agencies and their areas of specialty
- promotion of advocacy services to people with disability to increase knowledge that this assistance is available
- more work by advocacy agencies at the community/societal level rather than focusing on the service system
- funding an outreach model of advocacy where advocates would seek out highly vulnerable people so that advocacy resources are provided to those in greatest need
- a ‘hub and spoke’ model, i.e. a city centric large advocacy organisation with links to regional advocacy services
• NDAP recognition of the community education and development activities undertaken by advocacy agencies
• acknowledgement of the step before intensive advocacy, i.e. the provision of information and advice that may be all that is needed for the person or service to advocate for themselves
• clarity of the role of advocates
• clarity of advocacy principles
• establishing a national individual advocacy service with a team of advocates based in each state who are fluent in Auslan
• recognition of crisis prevention and early intervention strategies and reflection of this in funding
• succession planning process for coordinators/managers of advocacy agencies
• rewards and incentives for good advocacy practice.

A submission from a peak body recommended the establishment of a National Carers Advocacy Program (NCAP) to run in parallel with the NDAP. Advocacy agencies felt strongly that carers’ advocacy should be funded separately from advocacy for people with disability.

8.3 Indicators of Success
Advocacy agencies had some difficulty suggesting measures or indicators that the government should use to evaluate the success of the program at a national level. A common theme was a desire for more qualitative reporting of outcomes. The suggested measures or indicators were:

• client satisfaction
• consumers’ experience of services
• consumer accounts of the difference that advocacy has made
• a selection of success stories
• quality reviews
• external, independent, specialised evaluation of advocacy agencies e.g. Citizen Advocacy Program Evaluation (CAPE)
• Model Coherency Evaluation Tool (John Armstrong)
• consumer empowerment measured through three indicators: knowledge of rights; how much control; speaking up
• UK Richter Scale which one advocacy agency has modified for people with severe disability – individuals are assessed at intake and then reviewed after advocacy assistance has been provided
• indicators derived from the United Nations Convention of the Rights of Persons with Disabilities
• number of cases
• how long cases have been open
• waiting lists.

There was discomfort about the use of numerical counts such as number of consumers receiving advocacy support. One concern was that the use of raw numbers as an outcome or funding measure might encourage agencies to ‘push people through and not take on the more difficult cases’. A numerical measure was thought to be inappropriate for Systemic Advocacy. One submission described inflated counts, for example, an agency that provides other disability services in addition to advocacy, reporting all of their clients as advocacy clients.

There is a problem with funding contracts based on numbers, for example, how many clients did you see? There are no incentives to see a diverse population or to do more difficult work around fundamental human rights abuses. (Interviewee)

A combination of raw data and more qualitative data is needed. It has to be understandable to people who are not familiar with advocacy. (Discussion group participant)

Stakeholders raised the issue of comparability of outcome data across different types and levels of advocacy support. For example, outcomes achieved in dealing with ‘life and death’ issues could not be fairly compared with activities such as ‘assisting a person to fill in their Centrelink forms’.

Counts of the number of people receiving advocacy assistance may include cases of varying complexity and types of advocacy support. These factors can result in large variations in time, skills, resource requirements and cost. One suggestion was to introduce a simple classification system so that the degree of complexity could be reflected in the program statistics. For example, there could be three classification levels for Individual Advocacy support:

• brief interventions such as phone or email advice, information or referral requiring no more than 30 minutes of the advocate’s time
• longer interventions involving face to face meetings, multiple or complex issues requiring up to 3 hours of the advocate’s time
• complex, intensive and extended advocacy support involving multiple meetings and skilled support requiring more than 3 hours of the advocate’s time.

A level of support scale is apparently used in New South Wales.

Collection of consumer satisfaction data may not be straightforward.

Client satisfaction data is more challenging for advocacy. We don’t have a captive audience: once consumers have obtained the information or advice they need, they may not contact us again. Many of our consumers have literacy problems and would have difficulty with a written survey. Satisfaction can also depend on the consumer’s desired outcome and
whether this was realistic. (Interview with NDAP-funded advocacy agency)

Another challenge identified was the measurement of preventative advocacy outcomes.

FaHCSIA staff interviewed for this research project suggested the following indicators or measures for evaluation of the NDAP at a national level:

- compliance of NDAP-funded agencies with agreed quality standards
- numbers of people receiving advocacy assistance and demographics
- number of occasions of service
- additional data for Citizen Advocacy, e.g. new and ongoing matches
- qualitative information such as case examples
- issue/action/outcome data e.g. what the person came with, what the advocate did, what the person left with
- number of issues addressed
- follow-up data e.g. consumer’s situation at 3 months and 6 months after advocacy intervention
- client satisfaction
- complaints data
- results of campaigns or milestones of systemic advocacy.

FaHCSIA staff also expressed concerns about the use of numerical counts for this program.

Advocacy is too hard to just tie down to numbers. It is one of those softer programs where you need some more emotional information. (Interviewee)

Number of consumers is not a measure of success. Have the individual’s needs been met? Has the agency pursued the consumer’s issue to its conclusion? Did the agency help the consumer as much as it possibly could? (Interviewee)

The program could measure the percentage of consumers’ desired outcomes met, but this depends on the complexity of the challenge. (Interviewee)

FaHCSIA has a policy document titled Standard Performance Management Framework for Community Services Funded Programs (April 2009) which specifies the use of several indicators from a range of generic indicators. The Standard Performance Framework is to be used by program and project managers to select performance indicators for use in FaHCSIA Portfolio Budget Statements and Annual Reports, internal performance reports and funding agreements.
Of the performance indicators provided in the policy document, the following appear to be the most appropriate for a national advocacy program:

- Improved social inclusion (A7.3) – Percentage of communities with improved services systems to respond to the needs of vulnerable clients.
- Satisfaction with assistance received (B1.1) – Percentage of clients satisfied that the service they received met their needs.
- Goal attainment (B7.1) – Percentage of clients who met their individual goals in terms of [program-specific goals that clients set when they commenced receiving assistance]
- Participation and coverage (C1.2) - Number/percentage of clients assisted by geographical location
- Resource utilisation (C2.1) – Cost of providing services per client
- Service quality (C3.1) – Percentage of clients receiving service within quality standards
- Service quality (C3.4) – Percentage of service providers who meet accreditation requirements or relevant industry standards for service management and governance
- Service outputs (D1) – Number of clients assisted (per year) by output category
- Service outputs (D3) – Number of service sites by output category.

The Standard Performance Framework recommends that 4 to 6 of the performance indicators be selected.

There are no performance indicators relevant to Systemic Advocacy in the Standard Performance Framework document. FaHCSIA could consider the following indicators for evaluating and reporting on Systemic Advocacy at the national program level:

- Number of Systemic Advocacy issues on which progress has been achieved during the reporting period.
- Number of Systemic Advocacy issues which have been resolved or finalised during the reporting period.
- Percentage of Systemic Advocacy issues for which an action plan and/or critical pathway or program logic model has been prepared.
- Percentage of Systemic Advocacy issues which are supported by evidence and/or referrals from Individual Advocacy agencies.

Conclusions

Stakeholders consider that the current models of advocacy are appropriate for meeting present and future needs but that a more flexible approach is needed in the funding of advocacy services, i.e. not specifying in NDAP funding agreements the percentage proportions of the different advocacy models that agencies should provide.
There are gaps in the distribution of advocacy services and concerns about limited funding, inadequate networking and linkages, training needs and variable quality of advocacy service provision.

The modifications required to enable the NDAP and the advocacy models to meet the needs of people with disability involve:

- clearly defined aims for the NDAP
- focus on outcomes rather than models of advocacy
- nationally consistent principles, guidelines, standards and quality assurance for disability advocacy
- funding two main streams of advocacy: Individual Advocacy and Systemic Advocacy
- continued diversity in advocacy provision, including availability of specialist advocacy services for particular groups
- more effective allocation of Systemic Advocacy funding
- better linkages between Individual Advocacy and Systemic Advocacy
- stronger collaboration and networking between advocacy agencies
- improved training for advocates
- a three-year funding cycle
- consistent and streamlined reporting requirements across state/territory and Commonwealth government funders of advocacy programs.

Stakeholders have highlighted the difficulties involved in measuring the success of advocacy programs. A key issue is the recognition of complexity in numerical counts of advocacy contacts and interventions.

Performance indicators for the NDAP at a national program level will need to be drawn from FaHCSIA's Standard Performance Management Framework with additional indicators to be determined for Systemic Advocacy.
9.0 Overall Conclusions and Recommendations

Of the six models of advocacy funded under the NDAP, Individual Advocacy is the model that has the best potential to provide immediate advocacy assistance across a wide range of issues to the greatest number of Australians with disability.

This model needs to be interpreted in a more flexible way than is currently suggested by NDAP funding and administrative arrangements which indicate a clear demarcation between each of the six models of advocacy. Individual Advocacy should be the primary model of advocacy for the NDAP but should incorporate the flexible use of other models such as self, legal and family advocacy as appropriate to meet consumer needs. This is in effect already happening in many advocacy agencies. The focus of the program needs to be on outcomes for individuals and quality advocacy practice based on core principles that apply equally to all models.

Systemic Advocacy can be effective in achieving systemic change at local, state/territory and national levels and provides a valuable contribution to policy development. These systemic changes can bring advantages to large population groups and communities. Systemic Advocacy can also address recurring issues and potentially reduce the need for Individual Advocacy in the longer term.

Systemic Advocacy needs to be adequately resourced, informed by Individual Advocacy, collaborate with Legal Advocacy for legal and legislative issues and have pathways for feeding issues and information through to government decision makers at state/territory and Commonwealth levels.

A structured process for registering Systemic Advocacy issues on the government agenda would place the Australian disability advocacy system at the forefront of disability advocacy development.

The findings and recommendations of this research project suggest that the NDAP should fund two main streams of advocacy: Individual Advocacy and Systemic Advocacy. This system should be supported by:

- consistent advocacy principles and practice standards
- national Quality Assurance and accreditation processes
- collaboration, networking and training opportunities.

The place of Citizen Advocacy in this system is complicated by divergent views. Although the benefits of Citizen Advocacy are acknowledged, stakeholders have raised a number of concerns about this model, its sustainability and its inclusion in the NDAP. While existing citizen advocate:protégé matches that are working well should continue to be supported, there need to be good links to other forms of advocacy.

In terms of performance indicators for evaluating and reporting on the program at a national and departmental level, the NDAP is required to select from the performance indicators provided in the FaHCSIA Standard Performance Management Framework. As one of these performance indicators is 'percentage of service providers who meet accreditation requirements of relevant industry standards for service management and
governance’, the Disability Advocacy Standards and Quality Assurance process soon to be trialled for NDAP-funded advocacy agencies take on a critical importance in ensuring that quality outcomes are achieved for people with disability.

Recommendations

Having carefully considered the information and findings from all of the research activities undertaken for this project, including the views expressed by all stakeholders who participated in consultations, we make the following recommendations:

Recommendation 1
FaHCSIA should clearly define the aim of the National Disability Advocacy Program with the focus of the program to be on outcomes for individuals with priority to the most vulnerable people with disability.

Recommendation 2
FaHCSIA should develop an agreed set of principles and program guidelines on which advocacy funded through the National Disability Advocacy Program will be based.

Recommendation 3
FaHCSIA should fund two main streams of advocacy through the National Disability Advocacy Program: Individual Advocacy and Systemic Advocacy.

Recommendation 4
Individual Advocacy should be the primary model of advocacy funded through the National Disability Advocacy Program. Each agency funded to deliver Individual Advocacy should provide individual consumers with advocacy assistance undertaken by a trained advocate. Individual Advocacy for the purposes of NDAP should have a flexible definition enabling the additional use of, or referral to, a range of other advocacy models, such as Self or Legal, as required by consumers from time to time.

Recommendation 5
FaHCSIA should review the geographic map of advocacy services currently funded by Commonwealth and State/Territory governments to identify gaps in the availability of advocacy services.

Recommendation 6
FaHCSIA should review the current allocation and distribution of Systemic Advocacy resources. Over time, FaHCSIA should allocate NDAP funding for Systemic Advocacy to ensure that agencies funded to provide Systemic Advocacy have sufficient resources to effectively manage systemic issues and there is at least one Systemic Advocacy agency in each state and territory.

Recommendation 7
In consultation with the advocacy sector, FaHCSIA should develop a process for Individual Advocacy agencies to identify issues requiring Systemic Advocacy and a pathway(s) to feed these issues through to the appropriate Systemic Advocacy
organisations at state/territory and national levels and on to state/territory and/or Commonwealth government policy agenda.

**Recommendation 8**

In consultation with the advocacy sector, FaHCSIA should facilitate a National Systemic Advocacy Forum involving representatives of a national disability advocacy peak organisation, state/territory advocacy networks, national disability peak bodies (including consumer representatives) and relevant government representatives to consider systemic issues, examine supporting evidence, prioritise issues and provide appropriate input to government policy agenda.

**Recommendation 9**

The disability advocacy sector should facilitate regular professional development, collaboration and networking opportunities for disability advocates and governance training for Board members.

**Recommendation 10**

The disability advocacy sector should work with the Community Services and Health Industry Skills Council and State Training Authorities, to revise and improve the disability advocacy training standards contained in the Community Services Training Package.

**Recommendation 11**

FaHCSIA, state and territory governments and the disability advocacy sector should improve the advocacy information for consumers and advocates provided on government and agency websites and in other media. This information should include names and locations of government-funded advocacy agencies, types of assistance provided, agency contact details and links to networking and development opportunities for advocates.

**Recommendation 12**

FaHCSIA should consider introducing a three-year funding cycle for NDAP-funded advocacy agencies and ensure that funding agreements allow for sufficiently flexible advocacy responses to meet individual and community needs.

**Recommendation 13**

FaHCSIA should continue discussions through Commonwealth/State/Territory mechanisms with a view to addressing inconsistencies between Commonwealth and state/territory government funding policies and reporting requirements for advocacy agencies.

**Recommendation 14**

FaHCSIA should consider introducing a simple classification of level of advocacy support for the purposes of reporting the number of advocacy consumer contacts. This classification should differentiate between simple advocacy assistance such as brief telephone advice, information or referral and more complex and resource intensive levels of advocacy support.

**Recommendation 15**
FaHCSIA should continue with the process to trial National Advocacy Standards and an associated Quality Assurance and accreditation system.

**Recommendation 16**

FaHCSIA should use the following performance indicators from the *Standard Performance Management Framework for Community Services Funded Programs* (FaHCSIA, April 2009) to evaluate and report on the NDAP at a national level:

- Satisfaction with assistance received (B1.1) – Percentage of clients satisfied that the service they received met their needs.
- Participation and coverage (C1.2) - Number/percentage of clients assisted by geographical location
- Service quality (C3.4) – Percentage of service providers who meet accreditation requirements or relevant industry standards for service management and governance
- Service outputs (D1) – Number of clients assisted (per year) by output category.

These quantitative measures should be complemented by qualitative information including case studies, success stories and examples of best practice.

**Recommendation 17**

FaHCSIA should consider using the following performance indicators to evaluate and report on Systemic Advocacy at a national level:

- Number of Systemic Advocacy issues on which progress has been achieved during the reporting period.
- Number of Systemic Advocacy issues which have been resolved or finalised during the reporting period.
- Percentage of Systemic Advocacy issues for which an action plan and/or critical pathway or program logic model has been prepared.
- Percentage of Systemic Advocacy issues which are supported by evidence and/or referrals from Individual Advocacy agencies.