Australian Government Department of Families, Community Services and Indigenous Affairs

Evaluation of the
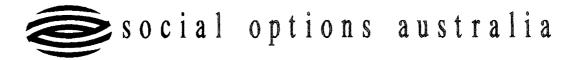
National Disability Advocacy Program
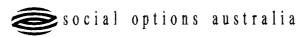
Final Report

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1   Executive Summary

The statement of requirement for this evaluation was to:

> *'Assess and make recommendations about current operations of the Advocacy program, against its stated goal and objectives and to propose recommendations aimed at addressing any identified shortcomings'*

The Commonwealth-State/Territory Disability Agreement 2002-2007 declares that advocacy for people with disabilities is a joint Commonwealth-State responsibility. The National Disability Advocacy Program is funded by the Australian National Government through the Department of Family, Community Services and Indigenous Affairs.

Methods employed in the evaluation included a review of selected literature, calls for written submissions, and direct consultations with people with a range of disabilities and from a variety of geographic and social backgrounds in all States and Territories, NDAP funded Advocacy Agencies, Business Services providers, Disability Peak Disability Bodies, FaCSIA NDAP program managers in State and Territory Offices, family carers of people with a range of disabilities, State and Territory government officers and other stakeholders and interested parties.

The evaluation has uncovered a wide number of areas in which the NDAP is badly in need of reform.

Currently advocacy for people with disabilities in Australia has a focus on disability rather than on human, civil or legislative rights. Historically the system has been seen as a disability issue, and rightfully belonging to the disability sector. This 'ownership' of advocacy for people with disabilities has clouded many of the issues, and has made it difficult for some to recognise that advocacy is essentially about rights.

Differences in policy and funding for advocacy for people with psychiatric disability exist among States and Territories. There is no clear definition of psychiatric disability which in some States is seen as a health issue, and therefore beyond the scope of disability advocacy.

A review of the NDAP in 1999 recommended that a distinction be made between individual and systemic advocacy. This has been accepted by the Australian Government and the thrust of the NDAP is towards individual advocacy. However unless systemic advocacy is properly and rigorously informed by work at the individual level, there is a risk that the weakest and least vocal systemic advocates or lobby groups will have difficulty in having their voices heard and issues addressed.

Currently the objectives of the program are not measurable and are not set out such that evaluation of the program can be made against them and some are unrealistic given the scope of the program.

Funding of advocacy agencies varies and many of the smaller advocacy agencies are having great difficulty in meeting the full costs of running the service which impacts on

their ability to provide efficiency and effectiveness. Some staff subsidise the program by paying for some costs themselves and working extra hours voluntarily. This is not sustainable.

People with disabilities lack information and understanding about what advocacy is available. Other barriers to advocacy are lack of knowledge about their rights and responsibilities, lack of accessible and affordable transport to an agency and particularly for those with an intellectual disability, discomfort in not talking with someone they know and trust and/or a fear of getting into trouble if they complain.

Geographic coverage is uneven and large rural and remote areas are not covered. Advocacy for Indigenous people with disabilities is the subject of a separate review, but needs are not well catered for. In the absence of factual data it is impossible to estimate the level of unmet need, but all stakeholders agree it is huge.

Stakeholders believe that all levels of government that provide disability services should contribute to the funding of advocacy, but the Australian Government should hold responsibility for overall management and operation.

There is little or no coordination between NDAP advocacy agencies and other bodies that provide advocacy, including those that advocate for people with disabilities. Relationships between advocacy agencies and service providers are tense. Advocates spend much time in carrying out welfare or case management work, which is properly the domain of service providers.

There are no standards relating to advocacy for people with disabilities. Advocacy agencies believe they should be provided with principles and/or guidelines. There is evidence to suggest that advocates may be unclear about their precise role.

There is currently no quality assurance system. Such a system would include measures to ensure: compliance with legislation; good governance; performance indicators including client access, satisfaction and outcomes and other measurements addressing service quality; staff training and professional development. A sound management system which encompasses reporting, client records and includes data to identify trends, systemic failures and inform policy needs to be introduced.

Currently advocates' priorities are determined by levels of crises and some agencies, notably Citizen Advocacy, are not geared towards the closure of cases. The complaints system is currently operated by one of the advocacy agencies. We understand it is subject to a separate review and full consideration should be given to transferring the work to a fully independent body within the framework of rights-based advocacy.

Comparison of international models indicates that quality service is achieved through a centralised system independent from service provision, and with local advocacy delivery. The disadvantages of having advocacy agencies which specialise by disability type outweigh the advantage but advocates need a thorough grasp of the issues facing people with different types of disability and the ability to call on expertise if necessary.

Delivery of advocacy services is considered best done as locally as possible. Outreach services, based on a 'hub and spoke' model and co-located with other relevant organisations is an appropriate model.

2   Recommendations

1. **That a uniform approach to what counts as a disability as it relates to advocacy services, particularly in regard to mental disorders/psychiatric disabilities, be taken in all States and Territories in line with the definitions given by the Australian Human Rights and Equal Opportunities Commission.**

2. **That as a principle individual advocacy to people with disabilities should be provided in collaboration with other advocacy organisations.**

3. **That as a principle advocacy should be provided to those people with disabilities who cannot advocate for themselves, in order that their human rights are upheld.**

4. **That through evidence-based research, the advocacy system identifies systemic issues which need to be addressed and inform policy development, so that the rights of people with disabilities are upheld.**

5. **That funding be reallocated so that all advocacy agencies are staffed by a minimum of 2.5 FTE advocates and 0.5 FTE administrative workers, and are able to meet the full overhead costs of running the service.**

6. **That a set of principles, standards of performance and good governance, and measurable, achievable objectives be developed in consultation with the advocacy agencies and other appropriate bodies**

7. **That the NDAP be developed with emphasis upon the human, civil and legislative rights of people with disabilities**

8. **That the Australian Government in collaboration with States and Territories instigate a public awareness campaign targeted at people with disabilities, their family carers and their service providers, on all advocacy options available to them (whether funded through the NDAP or not) to uphold their rights.**

9. **That proposals be invited from advocacy agencies within each State and Territory to operate under the same name which is easily recognised as an advocacy service for people with disabilities (such as 'Disability Advocacy Australia').**

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10. **That regional analyses be conducted to identify the levels of need for advocacy for people with disabilities in rural and remote regions of Australia.**

11. **That as a principle, prioritisation of advocacy resources be particularly directed to those people with disabilities who through difficulties in communicating (including reduced mental capacity) are unable to advocate for themselves.**

12. **That advocacy programs for people with disabilities be a shared and coordinated responsibility between the Australian and State or Territory governments, with leadership taken by the Australian government.**

13. **That responsibility for the funding and administration of the program be transferred to the Australian Government Attorney General's Department ensuring that the emphasis is upon the human, civil and legislation rights of people with disabilities.**

14. **That memoranda of understanding, or formal protocols and procedures, are developed with bodies in each State and Territory including but not limited to:**

    Public Advocates/Public Guardian

    Equal opportunity Commissioner

    Disability Commissioner

    Complaints Commissioner

    State Ombudsman

15. **That all governments provide further funding to resource the provision of services to people with disabilities on a case management basis, including intake and referrals to ensure that their issues are addressed and such that advocates do not spend their time on case management work.**

16. **That in collaboration with relevant State and Territory bodies, eligibility for advocacy is open to all people with disabilities who need advocacy support, no matter whether the issues be those of discrimination, complaints about FaCSIA-funded services, complaints about State or Territory-funded services, abuse and neglect, or based on the person's specific disability.**

17. **That clear advocacy guidelines be developed setting out standards, including good governance, training required of advocates and the proper role of an advocate, and disseminated to advocacy agencies.**

18. **That advocates be adequately trained in their role and all training includes a focus on the rights and the responsibilities of their clients, proper negotiating of differences rather than taking an adversarial approach, and the duty of care to their clients while acting in their best interests.**

19. **That in consultation with stakeholders the Australian Government introduce a uniform reporting system, preferably linked to a client management system, that gives measurable and useful information to both the agency and funders, identifies major issues for clients, and through which systemic advocacy and hence policy development can be informed.**

20. **That a review of the National Disability Abuse and Neglect hotline and Complaints Resolution and Referral Service should give full consideration to transferring the work to a fully independent body within the framework of rights-based advocacy and combining the hotline with an advocacy referral helpline.**

21. **That agencies tendering for funding be required to offer disability advocacy services on a generic basis, with opportunities to employ/utilise staff with knowledge and expertise in specific disabilities as required.**

22. **That the Australian Government establish a disability advocacy centre in each capital city, preferably co-located with other federally funded advocacy services such as Welfare Rights Centre, Aged Rights Advocacy Service or the Ombudsman's office.**

23. **That each capital city centre accept responsibility for:**

    administering, managing and supporting the advocacy service in their State or Territory

    undertaking evidence-based research and analysis of reports from their regional hubs (including reports from the local agencies) and hence identify service needs and systemic issues that need to be addressed

    ensuring that training for advocates (both paid and voluntary) be based upon National Workplace IV accredited advocacy training program and that this be the standard qualification for all advocates working in agencies funded through the program.

24. **That the model for advocacy agencies in the regions be on a 'Hub and Spoke' model, with regional hubs responsible to the centre located in the capital cities, with outreach or local advocacy agencies responsible to their regional hub.**

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25. **That the preferred model for delivery of advocacy services for people with disabilities within the regions be co-located within larger service agencies such as:**

   Community Legal Centres

   Community Health Centres

   Other Community Centres

26. **That outreach models of advocacy service delivery be encouraged in rural and remote areas, locally co-located with other similar services.**

27. **That where advocacy agencies have a high proportion of ATSI clients and client from a CALD background, staff have a thorough knowledge of cultural differences and the particular issues facing these clients.**

3   Introduction

3.1 Background

The Commonwealth-State/Territory Disability Agreement 2002-2007 declares that advocacy for people with disabilities is a joint Commonwealth-State responsibility with the National Disability Advocacy Program funded by the Australian government through the Department of Family, Community Services and Indigenous Affairs. The agencies operating within the program provide advocacy services on issues affecting the daily lives of people with disabilities.

The program was established after the introduction of the Disability Services Act 1986 with a mandate to provide advocacy services independent of direct service provision that would protect and promote the rights of people with disabilities. The program is an integral part of the rights protection framework which includes the Disability Discrimination Act 1992 as well as bodies such as the Human Rights and Equal Opportunity Commission, Offices of Legal Aid, the various offices of Public Advocate/ Public Guardian and Ombudsman Offices

In October 1998 a Steering Committee was appointed to review the National Disability Advocacy Program and the report on this review was produced in July 1999.

In essence, that report was concerned that the basic purpose or goal of the NDAP had not been established, and made recommendations concerning the major goal and identified eight main objectives of the Program.

The review expressed concern about the extent to which disability advocacy organisations should focus on the provision of direct services for their clients rather than focussing on lobbying policy makers and governments. It pointed to the fact that particular groups of people with disabilities were unable to access services and that increased service provision be targeted towards marginalised groups, particularly:

> Indigenous Australians
> Those with culturally and linguistically diverse backgrounds
> Those who live in rural and remote areas.

The review was also concerned that family carers should be given opportunities to advocate for people with a disability.

Although many of the recommendations of the 1999 NDAP review have been put into operation, there remained several key areas to be evaluated. Although this evaluation has taken the work and recommendations of the 1999 review into consideration, there are no necessary connections between the recommendations made in this report and the earlier review.

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3.2   The evaluation project

The statement of requirement for the evaluation project was to:

> *'Assess and make recommendations about current operations of the Advocacy program, against its stated goal and objectives and to propose recommendations aimed at addressing any identified shortcomings'*

There followed a list of twelve questions to be addressed in the course of the evaluation:

1   Are the existing advocacy services providing adequate coverage for the disability sector?
2   What is the estimated level of any unmet need?
3   Should the NDAP model allow advocacy services to specialise by disability type?
4   Do advocacy services have in place prioritisation strategies and case closure strategies?
5   What is the extent to which activities of advocacy services are integrated or coordinated with services provided by other organisations or other government departments?
6   What alternative delivery models should be considered that would enhance national coverage by the NDAP and at the same time deliver value for money?
7   How well does the NDAP compare to similar programs in other countries or those funded by State governments?
8   Is there justification to develop a set of standards that specifically relates to advocacy services? If so, what should these standards be?
9   What is the optimum quality management framework to ensure compliance with legislation and funding agreement requirements, while delivering quality advocacy services?
10   What input output and outcome measurements would be appropriate for advocacy services?
11. To what extent does the current level of funding constrain ability to meet the goal and objectives of the NDAP
12. Given that advocacy services are potentially funded from a variety of sources, what would be the optimum basis for their funding?

The Department of Families, Community Services and Indigenous Affairs made it clear that the evaluation was to explore issues of effectiveness and efficiently within the confines of present funding, notwithstanding the questions on levels of funding and the optimum basis for funding.

The evaluation was conducted over a relatively short time frame of seventeen weeks, with additional time allocated for consideration of the report by a Reference Group.

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4   Methodology Employed in the Evaluation

The NDAP operates within a highly complex environment and it was accepted that the evaluation should be confined to addressing the stated requirement and the twelve key questions in order to avoid becoming bogged down in the full range of service delivery issues for people with disabilities.   Requests for written submissions were therefore based on the twelve questions. However direct consultations ranged beyond them to cover a number of other issues considered relevant by FaCSIA officers and the consultants. Copies of the evaluations tools are contained in the Appendices.

4.1   Review of Selected Literature

Included in the methodology was an overview of selected national and international literature relating to disability advocacy. It explored a number of topics in relation to the key questions of the evaluation brief including some alternative models, and is included within the main body of this report under the relevant sections.

4.2   Written Submissions

Written submissions were sought from advocacy agencies funded through NDAP and disability peak bodies. A list of advocacy agencies funded under the program was provided by FaCSIA and each was contacted by email and invited to submit a written submission based upon the key questions listed in the brief.

4.3   Direct Consultations

Direct consultations were held directly with:
> Acting Chair, National Disability Advisory Council
> Advocacy Agencies
> Business Services providers
> Disability Peak Disability Bodies,
> Equal Opportunity Commissioner South Australia
> FaCSIA NDAP program managers in State and Territory Offices
> Family carers of people with a range of disabilities
> Public Advocate South Australia
> Representative of Community Legal Services
> Representatives of people with a range of disabilities and from a variety of geographic and social backgrounds across Australia
> State and Territory government officers
> Victorian Rural Disability Network

Consultations were held with staff from these organisations and their clients across a number of metropolitan, rural and remote settings. This allowed the consultants to hear directly from organisations, people with disabilities and family carers in a range of situations. Because of the relatively short time scale for this project, all consultations took place over two to four days in each location, in a series of visits to:
> Brisbane

Canberra
Melbourne
Sydney
Alice Springs
Hobart
Adelaide
Perth
Bendigo

This enabled the views of organisations, clients and family carers from a variety of cultural and geographical locations to be heard. It encompassed indigenous Australians from metropolitan and rural and remote areas, including those from traditional communities and people from culturally and linguistically diverse backgrounds including those who live in rural and remote areas. Fuller details of the tools used in the methodology are included in the Appendices.

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5   Definitions and Principles

5.1 Rights

Advocacy is essentially speaking up for the rights of others. Examples could be 'natural' rights, human rights, civil rights, and rights enshrined in legislation.

It is therefore the rights and issues around those rights for groups which need advocates that is important. The fact that various groups in society may need advocates to speak up for their rights does not necessarily mean that advocacy should focus above all on the details of those groups. What it does mean is that the needs and issues which face those groups need to be tackled.

Governments are obliged to uphold certain rights which have been deemed to be universal – that is, applicable to everyone simply by virtue of their status as human beings (Australian Government Attorney Generals Department, 2005). Internationally, progress towards a United Nations Convention on Human Rights for people with disabilities is currently being made.

Parsons' Australian 'handbook' of advocacy as social justice, points to inequities in power in Australia, and argues that the degree to which people might need, and be entitled, to the things that they ask for, is rarely part of the equation.   He observed in 1994 that advocacy should not be so much aiming to ensure that people with disabilities are valued against *existing* standards, but rather that those standards are challenged and that their essential injustice is exposed. He maintains that advocacy for people with disabilities becomes more than anything else, a political process of social change. (Parsons 1994).

Another Australian critic agrees that people with disability have long been pawns in the power struggle between a number of different sectors, which he terms the 'Empires of Disability Power'. These include the Medical; Psychology; Charity; Service provider; Special Education and the Bureaucratic 'empires' (Stone, 1997, National Council on Intellectual Disability p 13).

Currently Australian advocacy for people with disabilities retains this focus on disability, which is a normal part of the human experience (HREOC, 2006) rather than a focus on their human, civil or legislative rights.

5.2   Disability

Although there is some debate about the nature of advocacy, there are few definitions of disability in the policy or theoretical literature. Theorists evidently consider that everyone knows what is meant, regardless of an ongoing dialogue between critics on the worthiness of social constructionism, the social model of disability and the medical model (Gergen, 1985; Fine & Asch, 1988; Scotch 1988; Oliver, 1996, Bruzuzy, 1997; Donoghue, 2003).

Definitions of disability also vary among international jurisdictions. In Canada for example, the legislation defines disability as being either:

    Physical or mental

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> Previous or existing; and
> Including dependence on alcohol or a drug

In Canada as in Australia, a disability can be either permanent or temporary. (In determining whether a temporary illness would be considered a disability under the Canadian Human Rights Act, consideration is given to the effects the illness is alleged to have had on the complainant's employment or ability to obtain a service, not only the nature of the illness itself.)

Many definitions of what counts as a disability are not recognised internationally and there is confusion internationally and in Australia over the question of psychiatric disability.

Psychiatric disability can be considered as a condition arising from mental illness, in the same way that paraplegia and quadriplegia can arise from a physical trauma, such as spinal cord damage or a stroke. However, the distinction between psychiatric disability and mental health is often not made, and much of the recent literature either glosses over this issue or implicitly implies that there are no clear cut boundaries.

WHO Advocacy Guidelines (2003) note that the mental health advocacy movement is burgeoning in Australia as in other countries, but makes no distinction made between types or levels of mental disorders, which are all treated as mental illness rather than psychiatric disability (WHO 2003).

Ten years ago the World Psychiatric Association embarked on an international programme to fight the stigma and discrimination associated with schizophrenia. They showed how stigma creates a vicious cycle of alienation and discrimination which can lead to social isolation, inability to work, alcohol or drug abuse, homelessness, or excessive institutionalization, all of which decrease the chance of recovery (WPA, 1996).

Their worldwide compendium of programs aiming to reduce discrimination (WPA, 2002) makes a distinction between schizophrenia and other mental illness, but other international work (cf. World Health Organisation, 2001a) fails to define the boundaries between 'mental disorder' mental illness or psychiatric disability.

Similarly the Australian Human Rights and Equal Opportunities Commission's discussion of disability rights combines mental disorders, including depression with psychiatric disabilities such as schizophrenia (HREOC, 2006).

This is a very important point, as during the consultations for the evaluation it was very clear that differences in policy and funding for advocacy for people with psychiatric disability exist among States and Territories. Some treat anything relating to psychiatric disabilities, including advocacy for people with a psychiatric disability, as a mental health issue and therefore the responsibility of their Health Department.

This focus on the disability, rather than on the rights of the individual or group, leads to confusion. Inherent dangers exist. In particular it indicates the possibility that some people with disabilities, particularly psychiatric, may not find it easy to access an advocate if the system is geared to the medical model.

Also relevant in discussing what counts as a disability, is the role of culture in acknowledging differences between psychiatric disability as opposed to mental ill health. Cultural differences can also play a key part in acknowledging disability per se, either physical or psychiatric.

For example, literature from Western Australian (Ethnic Disability Advocacy Centre, 2000) reported on the needs of Muslim people with disabilities. It identified specific elements of stigma and shame associated with disability of any kind in that community. It also pointed to significant barriers to accessing services and advocacy for Muslim people with a disability in Australia, in large part due to associated shame, and hence the unwillingness to admit to disability for themselves or for members of their family.

5.3 Individual and Systemic Advocacy

The issue of the profound powerlessness of people with disability which has gone largely unrecognised and mostly not addressed and the need for the political action deemed necessary to correct this imbalance (Stone 1997) has been taken up by many advocacy organisations.

However, it is clear that the emphasis on political action and advocating for systemic changes at the political level rests uneasily with the sector funding service provision. One of the recommendations in the 1999 NDAP review was that a distinction be made between individual and systemic advocacy.   This has been accepted by the Australian National Government and has resulted in an official separation between the two forms of advocacy for people with disabilities.

Advocacy as the process of 'standing alongside an individual who is disadvantaged and speaking out on their behalf in a way that represents the best interests of that person' (Institute for Family Advocacy and Leadership Development: Cross: 1992) is clearly seen in terms of individual advocacy.   On the other hand the World Health Organisation's definition of advocacy for people with mental health issues as 'various actions aimed at changing the major structural and attitudinal barriers to achieving positive mental health outcomes in populations' (WHO, 2003) is clearly about systemic advocacy.

Definitions such as:
 'Speaking, acting or writing with minimal conflict of interest on behalf of the interest of a person or group in order to promote, protect and defend the welfare of and justice for either the person or group' (Disability Advocacy and Information Reform Project, 2003)
 and
Advocacy assists people to achieve and maintain their rights and provides support to individuals, families or groups in resolving issues that affect them.   Advocacy strives to prevent or stop abusive, discriminatory or negligent treatment; to increase personal or group well being; and to achieve social justice, equity of access and participation in the community' (Disability and Aged Information Service Inc NSW Advocacy Fact Sheet, May 2002)

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are clearly directed at both forms. In the USA a similar view is proposed by Kendrick, who points out that what we may miss is that advocates are frequently people who have become persuaded that the world can be better, and that it is incumbent on them to struggle for what might bring this improved world closer.

Following the recommendations of the 1999 review, funding for advocacy for people with disabilities in Australia has focused on advocating for individuals. Much of the systemic advocacy work is carried out by organisations geared to assisting their members who usually have a particular type of disability.

However despite the official distinction between the two forms of advocacy, the division has not been readily accepted in the sector.

Both individual and systemic advocacy are essentially about helping people achieve their rights. Although the tasks undertaken in order to do this may be different, both forms of advocacy are complementary and interdependent, and, as both in their own ways contribute to achieving those rights, neither should be compromised (Graffam, 2002).

Further, individual advocacy is effective in uncovering trends and driving significant changes at the systemic level.   As Queensland's Public Advocate maintains, systemic advocacy is nothing if not informed by the daily lived experience of vulnerable individuals (Boardman, 2004).

Nevertheless it needs to be reiterated that one organisation is highly unlikely to be able to carry out both forms of advocacy simultaneously. This is because the tasks and the skills needed by a systemic advocate are different from those needed for individual advocacy. Additionally, given that many of the smaller advocacy agencies in Australia are under resourced (see section on funding below), systems advocacy work will inevitably suffer 'in the face of the moral imperative to help the individuals walking through the door' (Boardman, 2004).

Unless systemic advocacy on behalf of particular groups is properly and rigorously informed by individual advocacy work, there is always a risk that the weakest and least vocal systemic advocates or lobby groups will be less likely to have their issues addressed.   So while it is important that the distinction between the two forms of advocacy remains, it is important that systemic advocacy should be evidence-based and that the work of individual advocacy form the basis of such evidence.

Consultations with FaCSIA Program Managers raised the view that systemic advocacy is valuable. They appreciated that the concerns are usually national issues but locally driven and it was felt that national funding needs to be provided for them to be pursued and addressed.

In summary, advocacy of all types, including advocacy for people with disabilities, is primarily concerned with the rights of individuals or groups.

If advocacy is primarily focussed on disabilities as it is in Australia, there are dangers that access to advocacy may be made more difficult for some, as what counts as a disability varies considerably.   In Australia, a temporary illness or dependence on alcohol or a drug

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is not generally regarded as a disability, although some communicable diseases are covered, but there is much misunderstanding of psychiatric disability and mental health issues. Some State governments departments do not recognise psychiatric disability as a disability and consider that this 'belongs' within the medical system.

It would seem that either the differences between 'mental disorder', 'personality disorder', 'psychiatric disability' and 'mental illness' need to be thoroughly defined, understood by and acted upon by all levels of government that fund advocacy services, or alternatively all people who have mental problems are included in a system of advocacy for people with disabilities.

Advocacy may mean lobbying for services and/or changes in government policy for some, short term interventions for individuals for others, while for yet others it is a long term effort in helping an individual and in the case of Citizen Advocacy (of which more below), virtually means having a friend for life.

While attempts have been made to separate out individual from systemic advocacy the fact is that the latter builds on – or should build on - the former. Although the evaluation brief focussed on individual advocacy, unless it is recognised that the two are intimately entwined, and unless systemic advocacy is based on objective, independent evidence and research, the most vulnerable people are unlikely to be heard.

We therefore recommend:

Recommendation 1: That a uniform approach to what counts as a disability as it relates to advocacy services, particularly in regard to mental disorders/psychiatric disabilities, be taken in all States and Territories in line with the definitions given by the Australian Human Rights and Equal Opportunities Commission.

Recommendation 2: That as a principle individual advocacy to people with disabilities should be provided in collaboration with other advocacy organisations.

Recommendation 3: That as a principle advocacy should be provided to those people with disabilities who cannot advocate for themselves, in order that their human rights are upheld.

Recommendation 4: That through evidence-based research, the advocacy system identifies systemic issues which need to be addressed and inform policy development, so that the rights of people with disabilities are upheld.

6   Is the NDAP Achieving its Objectives?

6.1 The Objectives

There are eight objectives of the National Disability Advocacy Program. These are:

1. Prevent abuse, discrimination or negligent treatment of people with disabilities
2. Promote and enhance the rights of people with disabilities
3. Encourage people with disabilities to make informed choices
4. Increase economic and social participation for people with disabilities in the community
5. Assist people with severe disabilities to participate equitably in community life
6. Increase the knowledge and understanding of people with disabilities their families and carers about the rights of people with disabilities
7. Improve communication between people with disabilities and other members of the community
8. Recognise, value and include families, and carers wherever possible and appropriate in the support system for people with disabilities

Some representatives of advocacy agencies were critical of the objectives of the program, with some describing them as 'motherhood statements' that cannot be measured.

Although the evaluation was not specifically asked to review the objectives, it is apparent that they are in need of reconsideration.

This is for two reasons. Firstly as things currently stand, there are no measurable and achievable desired outcomes against which evaluation of the program can easily be undertaken.

Secondly some of the objectives as they are written are unrealistic given the scope of the program. For example, the extent to which individual advocacy can *prevent* abuse, discrimination or negligent treatment of people with disabilities is doubtful.   This is because most advocates are approached because clients have, and probably still are, experiencing difficulties with events that have already occurred, and *prevention* of these events occurring in the future is beyond the scope of advocates. Systemic advocacy, legislation, public education and other arenas are better equipped to ensure prevention than individual advocates, who are called in when it is already too late.

Similarly, it is not realistic to expect individual advocacy to play a direct role in improving communication between people with disabilities and other members of the community.   Some degree of increased communication may result indirectly from advocacy efforts, but it is the role of advocates to uphold the rights of their clients, not to improve communication between them and other members of the community.

Further, the objectives make no mention at all of advocacy, of upholding rights, or what is expected of advocates. It is suggested that the objectives are reconsidered and revised to reflect these points and incorporate realistic measurable and achievable desired outcomes that can be evaluated against achievements in the future.

Consideration could perhaps be given to the following suggested principles.

Ensure that

In collaboration with National and State/Territory advocacy bodies the human, civil and legislative rights for people with disabilities who cannot advocate for themselves are upheld

In collaboration with disability peak bodies and other relevant stakeholders and through evidence based research, trends and systemic failures which negatively impact on people with disabilities are identified

People with disabilities, their carers and families, are encouraged to understand their rights as well as their responsibilities, the options available and thus make informed choices

People with disabilities are assisted to access services by which they can participate equitably in economic, social and community life

Families and carers wherever possible and appropriate are recognised and valued as an integral part of the support system for people with disabilities

6.2 Levels of Funding: To what extent does the current level of funding constrain ability to meet the goal and objectives of the NDAP

The 1999 Review of the NDAP stated at the time that levels of funding were not sufficient for effective advocacy for people with disabilities. Consultations and written submissions from all stakeholders during this evaluation have produced the same result.

Although it is appreciated that the Australian Government may not be able to increase funding for the NDAP, one of the key questions in the brief was whether the stated goal and objectives of the program could be met with current funding.

Without exception all the people interviewed about levels of funding and all of those who wrote submissions stated that the program was considerably under funded. Current funding is such that one of the Queensland advocates pointed out that there are 2.5 advocates for the whole of Brisbane.

Comment was made that funding for advocacy has actually decreased in real terms over the past five years with little increase in staff salaries and increased demands on agencies. An agency in northern Queensland with a large geographic area to cover, made the point that they have received no increase in funding for four years, when petrol was priced at 75 cents a litre. It is currently priced at almost double that amount.

In December 2005 the Victorian Disability Advocacy Network quantified the extent of what was termed a funding crisis, by describing the cut-backs that services are making and substantiating the impact of funding shortfalls. This coalition of approximately 35 independent community-based organisations argued that funding for disability advocacy in Victoria is insufficient to meet the increasing demands placed on services, with anecdotal evidence suggesting that services are significantly curtailing their activities to operate within their constrained budgets.

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The findings of the 2005 report were among other things that:
> *'there have been no funding increases to cater for rising real costs such as fuel, replacement or repair of capital equipment, increasing rent, award salary increases and spiralling insurance costs. Services have had to respond by reducing staff hours and therefore availability to support people, reducing travel to people, and seeking cheaper accommodation. Forced cost cutting has led to service quality trade-offs and appears to be eroding long-term sustainability'* (VDAN 2005*)*

FaCSIA program managers observed that many small agencies are struggling with administrative and reporting requirements. Fewer services with streamlined administrative arrangements were suggested. Other concerns expressed included:
> Minimal staffing with less than 1 FTE advocacy staff and less than .5 administrative assistance provides questionable client service
> The overuse of enthusiastic volunteers may disempower clients, some of whom may be able to self-advocate with training and support
> Questions of the training and professionalism of advocacy staff, the lack of supervision, mentoring or peer review along with unacceptable stress levels and burnout

The NDAP Service Overview for 2004-05 shows that of the 73 advocacy agencies then funded, 34 received less than $150,000 a year, with 18 receiving less than $80,000 a year.

This means that many of the smaller advocacy agencies are having great difficulty in meeting the costs of their overheads including rents, electricity, telephone etc which impacts on their ability to provide an efficient service. Indeed some agencies seem to be operating on the proverbial smell of an oily rag, to the extent that some staff subsidise the program by for example paying for fuel and other costs themselves and working extra hours voluntarily.

Some agencies have insufficient funding to employ advocates on a full time basis, although there are instances in which part time advocates work full time hours. Part timers and volunteers are used for a number of administrative and advocating tasks and direct consultations with advocates bears out the view expressed in the Victorian report that trade offs in the quality of service have had to be made. Sustainability of the program must be questioned in circumstances under which advocates are working in isolation from others and have some costs of running an office and service to bear themselves.

While it is not the role of this evaluation to recommend additional funding as was stated in the introduction, it seems evident that smaller agencies suffer negatively from economies of scale. Under such circumstances, agencies need a 'critical mass' of funding below which they cannot realistically operate efficiently and sustainably. We would suggest that at a minimum, an agency should be able to afford all the overheads required to run an effective service, and employ a minimum of 2.5 full time equivalent advocates and 0.5 full time equivalent administrative workers.

It is therefore recommended

Recommendation 5: That funding be reallocated so that all advocacy agencies are staffed by a minimum of 2.5 FTE advocates and 0.5 FTE administrative workers, and are able to meet the full overhead costs of running the service.

Recommendation 6:   That a set of principles, standards of performance and good governance, and measurable, achievable objectives be developed in consultation with the advocacy agencies and other appropriate bodies.

Recommendation 7: That the NDAP be developed with emphasis upon the human, civil and legislative rights of people with disabilities.

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7   Access to Advocacy and National Coverage of the Program

7.1 Knowledge of advocacy available

A decade ago, the review of the Commonwealth States and Territories Disability Agreement stated that there seemed to be considerable confusion between the categories of

> Policy advisory structures
>
> Advocacy on behalf of organised disability groups which may or may not be the same as peak body advocacy; and
>
> Rights-orientated advocacy services for particular consumers.

The review concluded that *'Many people with disabilities and their carers in Australia are unaware of what services they might access and or of the eligibility/ priority of access criteria that determine such access. Because disability services to date have not been well articulated as a well-coordinated system, it stands to reason there is no comprehensive service information provided on a system-wide level' (*Yeatman 1996).

However, the review's own suggested definition of advocacy as 'services which are oriented to the promotion, enhancement and protection of the rights *of disability service consumers'* (our italics) forms part of the problem of lack of access to advocacy for people with disabilities. The point here is that by confining advocacy for people with disabilities to those who are disability service consumers, a number of those who do not or cannot for some reason access those disability services, are left out altogether. There is no reason to assume that all people with disabilities receive the services designed to help them, and there is information available to indicate that they do not.

Currently there remains a plethora of services, some of which could be defined as advocacy services, in Australia. (A simple internet search in Australia of 'Disability Advocacy' lists a total over 400 websites.) These appear to be very unevenly spread and our consultations indicate that many advocates are unknown to people with disabilities, their families or carers, or even to some of the other advocacy agencies. Reference was made by FaCSIA Program Managers to lack of public knowledge that advocacy services existed but that if the existence of the service were known, many more people with disabilities would use it which might swamp the system.

Some of the reasons for this lack of knowledge are that services may not exist in rural geographic areas, or if they do, they are not geared to those most vulnerable. Or their existence is simply unknown. Direct consultations with clients and family carers asked them to share experiences of asking for help from an advocate. It was clear from consultations with people with intellectual disabilities that they had no real understanding of independent third party advocacy.

These clients included those who suggested that they could turn to their Business Services supervisor at work or his boss, or other support staff when they were living in supported accommodation. Some people referred to their family who would help them, and one client mentioned that there were some phone numbers available to 'talk to someone out of work', but it had not been used.

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However, one man with an intellectual disability told his story about when the house he shared with other clients was burnt out, and his two house mates forced him to do something that he considered wrong. The matter went to a Tribunal and the two housemates got a warning 'don't [do that] again, or you'll get the boot!' It was unclear to the client whether or not an independent advocacy agency had been called in to handle the incident.

Apart from lack of information and lack of understanding about what advocacy is available, and the lack of some services available to people with disabilities, another part of the problem in accessing advocacy may be due to the limits in the legislation governing it. Celebrating ten years since the passing of the Disability Discrimination Act, the Human Rights and Equal Opportunity Commission Report (2003) gave an account of around 5,500 complaints lodged under the Disability Discrimination Act during the decade. This is hardly a massive achievement for a national statutory body to cover over ten years, and the Commission states that not all of these complaints have been satisfactorily resolved.

One reason for this is that the Commission may only investigate complaints due to *discrimination* and no other reason. Indeed it has been rigorous in applying its power to decide *not* to deal with complaints that do not raise a *substantial* issue of discrimination or could be better dealt with by some other statutory authority. The HREOC report acknowledged that there are areas where individuals and advocates have expressed concern and frustration over the limits to the legislation. It reports the stressful and time consuming effort put into advocacy work, which at times is unable to deliver the best of outcomes they were looking for (HREOC, 2003).

The same limitations can be said to be true of State and Territory statutory bodies such as Public Advocates, Public Guardians, Ombudsman's Offices and other Commissioners, each of which have their own specific areas of operations which may vary from one State and Territory to another.

Access to advocacy by people with disabilities is therefore not only currently limited by lack of information about what advocacy is available, as was noted a decade ago in the 1996 review, but also by confusion over the different titles of advocates, who is responsible for what, and rigorous gate-keeping through eligibility criteria of the system designed to help them.

7.2 The Barriers: How are people prevented from accessing advocacy services?

During the consultations, advocates talked about clients' problems with isolation, the lack of availability of telephones in a private area for clients to contact them, lack of transport, along with lack of knowledge and information about access. Issues of literacy and language were also mentioned. Sometimes the nature of the disability it itself can mean that difficulty with communicating is a problem. Others stated that concepts of advocacy were not always understood and people did not know how an advocate could assist.

The most vulnerable people are those who are hidden and have little or no access to the outside world. Advocates pointed out that family carers and service providers may

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actively discourage or prevent a person with a disability accessing an advocacy service, believing that they know best. They stated that many service providers have no wish to have advocates involved, as the matter then becomes adversarial. Some advocates spoke about retribution for clients and family carers if the client complains.

It has already been noted that there is a general lack of knowledge and information that advocacy agencies are available.   Enlarging on this point was a view that some people with physical disabilities may not recognise that advocacy is available to them because they may not use a wheelchair. In other cases particularly those with an intellectual disability, people will most often go to someone they know and trust. In this case, that is most likely to be a staff member of a service provider. Lack of transport or the high costs of transport were also considered a factor in preventing those who do have some knowledge of advocacy agencies, particularly as so many geographic areas have no advocacy coverage available.

Indigenous advocates felt that there is a fundamental lack of understanding about the nature of advocacy support required by Aboriginal and Torres Strait Islander people with disability. They considered that the advocacy required is not often short-term, as issues are complex and require ongoing and flexible approaches that do not always fit a traditional advocacy model. They maintain that it is common for an Aboriginal or Torres Strait Islander person with disability to require support for their whole life which will include all aspects of the individual's existence, such as housing, education, employment, access to adequate nutrition, access to transport, access to health services and any number of other important facets of a person's life. The extent to which such support is properly the role of an advocate or is a broader form of 'welfare' case management and service provision is clearly an issue.

A group of profoundly deaf clients explained that there is very little support given to them not just for advocacy but for any other services, so they have to rely on their own resources. This is very difficult and there have been cases when an advocate has insisted that the client pay for an interpreter.

As a case in point, a group of deaf workers who were laid off had to register and sign on with Centrelink, but experienced great difficulty in finding out and understanding the system in the absence of an interpreter or someone who could explain to them how it worked. Centrelink may sometimes be able to supply interpreters, but if the client has to pay for the services, they may have to do without.

As one deaf person put it:
> *'The struggle, the stress in getting interpreting help – you have no idea! It's very important – I need help for seeing the chemist, banking, making a will. They used to come to the Australian Association for the Deaf asking for signers but who pays?'*

It is very clear that difficulty in accessing freely available interpreters is a significant barrier to accessing advocacy for this group.

During the consultations, those clients who had not used an independent advocate were asked if that was because they felt no need for one.   It emerged from some of the clients with an intellectual disability that there was some fear of retribution, and that on some

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occasions they had to be careful what they said. As one client put it: "*you have to think before you do anything before it blows up*.' A woman who worked in the library of her service provider had experienced a negative response to her effort to ask for help, and so had been reluctant to talk to any manager higher up the hierarchy, for fear of losing her job. However, others stated that all their supervisors were very approachable and open with them.

Some FaCSIA program managers noted that people with disabilities can be actively deterred from using the service by employers, by carers and by family members and thus their complaints remain hidden. Some provided anecdotal information confirming that some clients and their family carers are also wary of accessing advocacy services for fear of retribution from service providers.

Clients from various ethnic backgrounds found that the barriers to services and advocacy were usually misunderstandings, because of the language problem and lack of knowledge of the service providers. In common with other clients, most did not understand the system as a whole and which agency would be most appropriate. As they stated,

> '*there are too many services and not enough explanation about what they all do: you have to go to one service to another, and you don't know which way to turn*'.

One family carer argued passionately that there are advocates who push for their own agendas without the instruction of the people for whom they are advocating.

At the most basic level, another barrier to access is the fact that advocacy agencies operate under a wide variety of names or acronyms. Many of these do not contain the words 'advocacy' or 'advocate' and it is therefore unlikely to be recognised for what it is from the name.

Agencies stated that they do not advertise because they would not be able to cope with the flood of referrals. It is of great concern that currently clients may be discouraged and prevented from seeking assistance from advocacy services even when they are available.

7.2.1 Clients' understanding of their Rights

During consultations, clients were asked how well they considered they understood their rights and responsibilities.   Those working in business service agencies understood their responsibilities *as workers* very well. These were explained by one client as :

> '*You have to be prepared to turn up for work, and be multiskilled and capable of taking on responsibility and a variety of things. I understand that well and I'm happy where I'm working and I'd like to further my position in [the agency] and move up to advance myself. We're all aware of those and I don't have any issues*'.

None of this particular group mentioned their rights as clients, but another group of people with intellectual disabilities working in a business service agency stated that they had indeed been told of their rights to say what they wanted and the right to complain. They felt that they needed more information, or a refresher to make sure that they all did understand.

The majority of those born deaf (particularly those to hearing parents, who have no knowledge of the 'deaf culture') have a very low level of education, rarely extending

beyond Year 8, with a reading level well below that. Hence many deaf people have no idea of the legislation and rights under legislation. Some may have heard of the DDA but that is the limit of their knowledge. Legal issues can arise at any time and because deaf people are not aware of their legal rights, tend not to be assertive and lack an understanding of the processes in mainstream society, they are clearly at a great disadvantage.

Understandably given the circumstances, not many of those people with disabilities from culturally and linguistically diverse backgrounds had a clear understanding of their rights. However, one of the specialist ethnic advocacy agencies holds a monthly meeting at the agency specifically to inform clients about their rights.

Many people from culturally and linguistically diverse backgrounds have been held in detention centres and have ongoing issues with the Department of Immigration. This has resulted directly in high costs to them in both financial and mental health terms. All of these people had horror stories to tell, and were pleased to talk about the ways in which the advocacy agency had been able to support them. A Scotsman with an intellectual disability who was placed in detention for a number of years and who had suffered mentally as a result was not untypical of people with disabilities from overseas and their recent histories.

7.3 Are the existing advocacy services providing adequate coverage for the disability sector? Geographic coverage

Although the National Disability Advocacy program is a national initiative there are many geographical areas which remain uncovered, not all of which are in rural or remote areas.

Funded agencies have had their service agreements rolled over each year while overall funding does not reflect the population of people with a disability (National Disability Advocacy Program 2004-2005 Service Overview). Indeed decisions about which services will be funded appear to be based largely on history with 22 in Victoria (mostly for clients with intellectual disability), 18 in NSW and 8 in Queensland. This reflects great unevenness of coverage.

The consultations held with FaCSIA State and Territory Program Managers revealed that cover is patchy not only in regional, rural and remote areas but also in some parts of metropolitan cities (notably Melbourne although regional Victoria seems well covered). In Queensland, there are four services in Brisbane and another four in regional areas - Cairns, Mount Isa, Townsville and Sunshine Coast, leaving large areas of the state with no accessible service.

In Western Australia all advocacy agencies are concentrated around Perth and the South West with the most northerly being based in Geraldton. Consequently there is very little coverage of large areas of Western Australia although advocates try to liaise from a distance with State Local Area Coordinators. In South Australia all services are based in Adelaide, although some (MALSSA, Family Advocacy) visit country towns. Similarly, in the Northern Territory one service is based in Alice Springs with outreach to Tennant Creek and one in Darwin with outreach to Katharine. Another service is available in the NPY lands.

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Consultations with some FaCSIA Program Managers raised concerns about the lack of provision of advocacy services to Aboriginal and Torres Strait Islander clients. Opinions were that there is little understanding of disability issues among ATSI people, their needs or their rights under national legislation, let alone concepts of advocacy. A separate review of advocacy services for ATSI clients with a disability is currently being conducted.

State and Territory managers all concurred with their FaCSIA counterparts that the present program is insufficient geographically, particularly in rural and regional areas. Their observations of the nationally funded program emphasised all the issues raised by FaCSIA managers. In addition, all noted that advocacy agencies were not constrained to provide assistance in connection with nationally funded services, but that by far the majority of their work was in advocating for people with disabilities who are discontented with State or Territory funded services.

Uneven funding of the Program has led to some State governments providing top up funding to federally funded agencies and in some instances, funding additional agencies in response to lobbying by particular disability groups. The real and perceived conflict of interest inherent in these arrangements is recognised by the State managers but mostly dismissed as less important than trying to fill the gaps in provision of disability advocacy services.

While all the State government managers consulted noted that the current program does not provide national coverage, of particular concern is the widely expressed view that the program is not assisting people with disabilities in having their rights under existing legislation met and their complaints remedied. Consultations and written submissions from advocacy agencies, peak bodies and business service providers also showed overall agreement that advocacy is inadequate in its geographic cover.

A woman with a disability in Queensland who has on many occasions needed someone to advocate for her, stated in her written submission that she has never used one, simply because there has been no one in her area (the Atherton Tablelands) to turn to. As she argued an 1800 number or a readily available up to date list of state and national advocates available would be most useful.

7.4 Other gaps in coverage

Apart from large geographic areas without access to advocates, several FaCSIA officers also drew attention to the paucity of advocacy services for people with psychiatric disabilities and the challenges presented by this group of clients who straddle the health/disability services. Significant gaps were also identified in advocacy provision for people with intellectual disability and acquired brain injury.

Indigenous people with disability were also identified as having minimal access to advocacy services. An advocacy agency for indigenous people with disabilities explained that there are few non-indigenous advocacy services that are meeting the needs of Aboriginal people in any significant way. This occurs for a variety of reasons including:
1. Distrust on the part of Aboriginal people of the service system in general.

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2. Distrust on the part of some non-indigenous service providers of Aboriginal people.
3. Discrimination including racial discrimination particularly in regional and remote communities.
4. A belief or perception that Aboriginal people 'look after their own'.
5. A lack of understanding of how to deliver a culturally appropriate advocacy service.

Clients from culturally and linguistically diverse backgrounds have difficulty in accessing advocacy services often because the role of advocates is unfamiliar, and frequently there are issues of culture and language to overcome. Payment for interpreters is a huge drain on agency resources where they cannot access volunteers who speak the language, including signing, of the client.

The consultations provided evidence that many clients need legal advice but this is rarely available from government funded legal services.

Gaps in coverage often mean that service providers become advocates by default. One of the business service providers use one of their staff as an advocate because there are no 'other' advocacy services the client can access. Another found that the local Centrelink Disability Officer, Community Centres and Social Workers lacked an understanding or the necessary skills and made what the service provider considered poor decisions for or on behalf of their clients.

Lack of advocacy for family members caring for a person with a disability was also considered in a lengthy written submission from a family carer in New South Wales, who considered that the dominant voice of family carers is led by those looking after elderly people, and consequently there is little or no advocacy coverage for families servicing the living requirements of people with disabilities under 65 years.

7.5 What is the estimated level of any unmet need?

When asked to estimate the level of unmet need, neither FaCSIA Program Managers nor State or Territory managers were unable to provide answers other than *don't know*, *huge* or *immense, impossible to know*.

Particular concern was mentioned in regard to issues of legal discrimination (with one respondent stating that 95% of these complaints are not being addressed) and little comprehensive attempt to ensure that the rights, ambitions or aspirations of people with disabilities are met. Further concern that there is little attention being given to systemic advocacy was expressed and that this needs to be resourced.

Peak bodies and advocacy agencies were agreed that the levels of unmet are very high. Evidence given during the consultations shows that peak bodies are taking on a steadily increasing number of individual cases over the past few years. This is especially so in Tasmania, where young people with disabilities, those with acquired brain injury and those with mental health issues were identified as those increasingly needing advocacy.

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The agencies stated that particular disability types are prevalent - such as intellectual disability and psychiatric disability - but in many instances advocacy services are not available for them. An example was quoted stating that only $19.90 for each person with intellectual disability is available in a given area for advocacy services, assuming that each would want to access the service.

In summary, the evidence shows that access to advocacy and national coverage of the program is uneven. The level of knowledge about advocacy available among potential clients and their family carers is low, and is likely to be compounded by lack of understanding of the various State and Territory bodies, including Public Advocates, Equal Opportunity Commissioners and Ombudsmen which offer advocacy to people with disabilities, and the different names, including acronyms, under which the various advocacy agencies operate. It would be helpful for those who need an advocate if public awareness about what advocacy is available from where was more widespread.

Although it is clear that there are large areas of Australia where advocacy may be needed, it seems that no research has been undertaken to investigate the extent of that need, or what precise areas have most need. It is therefore considered that needs analyses should be carried out to determine what is needed and where.

Apart from geographic coverage, the evidence given shows that particular groups of people with disabilities are not accessing advocacy. These are those with psychiatric disabilities, who may fall between the health–disability service gap, those with an intellectual disability, acquired brain injury, indigenous people and those from culturally and linguistically diverse backgrounds, which can include deaf people.

It appeared impossible for FaCSIA or State and Territory government managers or any of the other stakeholders to estimate unmet need and none were willing to do so. The extent of unmet need cannot be established without an analysis being conducted of people with disabilities on a national basis and assessing their need for advocacy services, which should be done through relevant and rigorous research.

Knowledge of advocacy services among clients is poor. Agencies operate under various names and do not widely publicise their services for fear of becoming overwhelmed.

 It is therefore recommended:

Recommendation 8: That the Australian National Government in collaboration with States and Territories instigate a public awareness campaign targeted at people with disabilities, their family carers and their service providers, on all advocacy options available to them (whether funded through the NDAP or not) to uphold their rights.

Recommendation 9: That proposals be invited from advocacy agencies within each State and Territory to operate under the same name which is easily recognised as an advocacy service for people with disabilities (such as 'Disability Advocacy Australia').

Recommendation 10: That regional analyses be conducted to identify the levels of need for advocacy for people with disabilities in rural and remote regions of Australia.

Recommendation 11: That as a principle, prioritisation of advocacy resources be particularly directed to those people with disabilities who through difficulties in communicating (including reduced mental capacity) are unable to advocate for themselves

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8   Funding Arrangements

Almost a decade and a half ago, Australian critiques of funding arrangements called for full independence for organisations advocating for people with disabilities. A network of local 'informal collectives' was called for, with people sharing roles and responsibilities and which avoided funding from government departments that also funded services agencies. At the time it was argued that such a system leads to advocacy being perceived as yet another service, and further, that funding for advocacy was seen as being directly taken away from service provision (Cross, 1992).

The NDAP is currently funded by FaCSIA through the Commonwealth States and Territories Disability Agreement and managed by the Department through program managers in each State and Territory. Liaison with the States is achieved through officers nominated by State and Territory governments. Service agreements, reporting and auditing arrangements are handled by FaCSIA. A joint duty of care between the Australian Government and those in the States and Territories is expressed in the Commonwealth States and Territories Disability Agreement.

In consultations, all the FaCSIA Program Managers interviewed agreed that the States should contribute directly to funding the Program, with one suggesting that financial commitment should be sought from across departments providing services to people with disabilities. One respondent suggested that additional funding be sought from business and philanthropic institutions. Another suggested that professional bodies contribute, giving the example that the Institute of Architects should be invited to assist in fixing up problems with the built environment.

FaCSIA Program Managers were agreed that the Australian Government should continue to manage the NDAP, because:
> the States are the main service providers and that provision of advocacy services by them creates an immediate conflict of interest
>
> the Australian Government has an obligation to ensure that Commonwealth legislation (The Disability Discrimination Act) is complied with and that the program should be part of that compliance system
>
> only the Australian National Government can ensure consistency and coverage across the nation

State and Territory Managers were more disparate in their views, although nearly all thought the Australian Government should retain overall responsibility for the funding and management of the program. They consider this is the only way to ensure consistency of cover across the nation and emphasise the rights of people with disabilities and all the reasons listed above which were raised by FaCSIA Program Managers. Only one suggested that the program be handed over to the States and Territories within the Commonwealth States and Territories Disability Agreement. Another stated that case based funding (as is the basis for Business Services) should be explored. Three stated that the current joint approach be developed between the Australian Government and States, but with more collaboration and consultation.

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Some State governments provide additional top up funding particularly for rent, for example six agencies in Victoria and one in the Northern Territory.   In the financial year 2004-2005 State governments added $4 million to the $12.4 million provided by the Australian Government.   In addition two States are providing funding for disability advocacy to agencies that are outside the national program.

Since several government departments at both National and State and Territory level provide services to people with disabilities, it seems reasonable that they could contribute to the system of advocacy.   The possibility of attracting funds from business or philanthropic bodies could possibly be explored, but in reality, funding is best provided by the taxpayer with the majority contribution coming from the Australian National Government.

When asked about alternative funding arrangements, the advocacy agencies agreed that all governments should contribute with all departments providing services to people with disabilities required to contribute.   The majority directly consulted wanted responsibility to remain with the Australian National Government with seven suggesting responsibility be transferred to the Attorney General's Department and one thought the Australian Human Rights and Equal Opportunities Commission should accept overall management of NDAP.   Only two thought that the States and Territories should take over.

Written submissions also largely called for Australian Government management and funding, and the overall comment was that the program must remain independent.

Likewise, the majority of peak bodies consulted consider that the Australian National Government should be responsible for driving the agenda and for the overall funding of advocacy.   Criticism was levelled at the Australian Government for not taking a greater interest in disability as a whole, and some considered that funding should be along the same lines as the Aged Care program, where advocacy is rights orientated, rather than service related.

On the whole business service providers also felt that funding should rightly lie with the Australian National Government.   However a minority of service providers considered that funding should not be a FaCSIA issue, but rather should lie with the State governments, while others considered that as the issue can be many-layered concerning both state and national issues, the funding should reflect that and be a joint responsibility.

Overall the consultations and written submissions considered that responsibility for major funding of the NDAP should be the responsibility of the Australian Government. However, the extent to which this should come through FaCSIA or through another Department had not been considered in any depth.

The issue of independence played a major part in the reasoning of those who were opposed to State and Territory funding. The overall view was that State and Territory governments which are responsible for service provision should not also have major responsibility for advocacy, as independence from the funders would be compromised. The same argument can be applied to FaCSIA, which has responsibility for funding Business Services for people with disabilities, and hence could be seen to compromise the independence of advocates.

Bearing in mind that the principle of advocacy lies in ensuring the rights of individuals and groups are upheld, rather than focussing on the disabilities of the people who need an advocate, a logical argument would place responsibility for funding and management of advocacy under the Australian Attorney General's Department. This is a recommendation that has been made in the past but not acted upon.

It is therefore recommended:

Recommendation 12: That advocacy programs for people with disabilities be a shared and coordinated responsibility between the Australian and State or Territory governments, with leadership taken by the Australian government.

Recommendation 13: That responsibility for the funding and administration of the program be transferred to the Australian Government Attorney General's Department ensuring that the emphasis is upon the human, civil and legislative rights of people with disabilities.

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9   Working Arrangements

9.1   The extent to which activities of advocacy services are integrated or coordinated with services provided by other organisations of other government departments

Following the last review of the National Disability Advocacy Program (1999) responses to the review appeared in the literature. The disability journal *Access* (Volume 4 2002) was dedicated to responses to the review from a variety of authors, including academics, advocacy providers.

An overview of these articles shows that relationships between levels of governments and between governments and advocacy providers were at the time poor, with many tensions and misunderstandings between them (Kokocinski; Camela and Hand 2002). Much of this literature calls for more positive attitudes between the relevant parties, more open communications, and a firm resolve to tackle friction.

Consultations with several stakeholders for this evaluation revealed that the situation remains much the same. There are neither formal nor informal processes in place which allow for liaison between advocacy agencies and statutory bodies at State and National levels. No agreements exist for example between disability advocates and Guardianship Boards, Public Advocates/Public Guardians, HREOC, or Equal Opportunity Commissioners. There is no evidence of cooperation between FaCSIA funded advocacy agencies and those operated through State Governments.

Both FaCSIA and State managers called for better coordination between the levels of government and better information flow between the various relevant bodies. Several suggested that the Complaints Resolution and Referral Service operates outside the NDAP system and that formal links should be developed. One state reported the establishment of links with bodies such as Workers Compensation and transport authorities. Both groups wanted closer links and formal relationships in place in a number of directions, including local links between FaCSIA Program Managers and the State Public Advocates/Public Guardians and with Ombudsman at both State and national levels.

During consultations with State government managers the majority expressed concern over lack of trust between advocates and service providers. Evidence was heard of Boards of management operating secretly. Some of this enmity was put down to differing views and misunderstandings about the role of advocates and models of advocacy used. This was confirmed by both advocates and business service providers.

During the consultations, business service agencies were specifically asked what their relationships were with advocacy agencies. Overwhelmingly, they agreed that relations between the two groups were poor and in several instances hostile. The CEO of one business service provider went so far as to remark that advocates were a pain in the arse and made to make his life miserable.

In some cases relations have become soured due to individual advocates taking an adversarial stance towards the service provider when advocating for a client, or other

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instances when advocacy agencies have refused to take on a case.   One organisation accused advocacy agencies of taking a 'martyr' approach in their relations with service providers. Other instances were given about 'unusual perceptions' of some advocates in issues of client and/or family choice. One example was the case of a client who refused to pay his library fines, which the advocate saw as the client's choice. In the service provider's view this was not helpful to the client, and directly opposed their efforts in training clients about their responsibilities, and educating them to avoid isolation from society.

Despite the almost inevitable tensions that can arise when advocacy agencies are required to take action against a service provider agency, it appears that much depends on individual advocates and the way in which they operate. A positive relationship exists between the Disabled Workers Union and one of the major business service providers in Western Australia, largely because of the conciliatory approach and negotiation skills of the one advocate who makes up the organisation.

In reality, advocates find themselves at odds with service providers when services are scarce. Frequently they are advocating for an individual to be given a priority when there is already a waiting list and this leads to immediate conflict, and in practice results in one person being out up a waiting list at the expense of another who may not have an advocate.

Relationships between the funders at both levels of government and the advocacy agencies varied but on overall they are not close.

On the other hand there was general agreement that FaCSIA funded advocacy agencies collaborate between each other. There are some opportunities for networking and conferences although funding is not always available. Citizens Advocacy agencies in particular reported close collaboration with each other.   An example of close co-operation combined with a mentoring relationship exists in New South Wales between Aboriginal Disability advocacy and People with Disabilities. This is said to be culturally appropriate, and works well. The Aboriginal Disability Network NSW has recently supported the formation of the Indigenous Disability Network of Queensland and has ongoing relationships with Networks in Western Australia and South Australia.

During the consultations with advocacy agencies it was plain that some of the advocates were meeting for the first time, and in fact some had no prior knowledge of each other. So although collaboration seems to occur, there are some advocates working in isolation with little or no interaction with others.

Advocates reported very mixed relationships with other agencies when the service needed by the client is not available. However, several reported good working relationships with Centrelink. Advocacy agencies in Western Australia work with and sometimes even refer clients on to Local Area Coordinators employed by the Disability Services Commission on case management, and working relationships between the two groups vary. WA advocates considered that in some instances the Local Area Coordinators may undertake advocacy for clients, but agreed it was a grey area.

One of the very small advocacy agencies stated that:

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> *'We make contact with Centrelink for them, also Disability Services Commission, People who Care, employment agencies, accommodation services, Minister for Housing, Perpetual Trustees, Australian Taxation Department, welfare groups, Mental Health Services, arrange appointments with doctors, psychiatrists and dental (practitioners), validate monthly transport tickets, and also contact parents, guardians, carers and workshops'.*

This not only shows the number of services this advocate works in relationship with, but is also an indication of the work more properly carried out by disability services but which many advocates undertake.

Relations between regional disability peak bodies and advocacy agencies appear to vary considerably. Some relationships appear to be collaborative, but there are differences across States. Some peak bodies circulate news and information to a broad range of advocacy agencies, and while this may not be reciprocated there is recognition that advocacy agencies often lack the capacity to respond.

The point should also be made here that coordination with services provided by other organisations or government departments needs resourcing. A South Australian agency stated:

> `*Over the last 24 hours we have been requested to provide advocates for a number of initiatives such as [a] monitoring arrangements for residential/boarding houses [b] mandatory restraint procedures under the S. A. Mental Health Act and [c] representing people with a mental illness with the Diversion Court. Likewise FaCSIA has also requested SA advocacy organisations to participate in Disability Employment Assistance reforms. Advocacy organisations, whilst willing to collaborate on such important initiatives, do not necessarily have the spare capacity or specialist staff for such additional work.'*

All told, collaboration may be limited by lack of system coordination at the State and Australian Government levels, although this varies between states.

So although there is some evidence of collaboration and linkage there is less than is desirable. The information provided indicates that much more needs to be done to ensure that the rights and needs of clients remain paramount and that Australian and State governments work closely with advocates and service providers.

There appears to be little planning or coordination of advocacy at State and Territory or national level, with a number of statutory bodies involved in advocacy for people with disabilities, each with their own areas of specialisation, and having barely any contact with the advocacy agencies.

Community legal services which also advocate for people with disabilities also appear to have few links with advocacy agencies, and there appear to the variable arrangements with the national CRRS and National Disability and Abuse hotline. In this context, working relationships are often non-existent.

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Formal arrangements such as memoranda of understanding, protocols and procedures are required, particularly with statutory bodies established to ensure that the rights of people with disabilities are upheld.

9.2 Current common topics of advocacy:

Advocates are often asked to assist in accessing accommodation or dealing with homelessness, accessing allied health services, accessing education facilities - all of which are State issues.   In the Northern Territory basic issues such access to primary education, allied health care and physical aids such as ramps, wheelchairs and crutches were a major issue for people with disabilities.

Advocates also receive referrals from people with disabilities needing assistance with applications for income support, complaints about aged care being used for young people with disabilities, complaints about aged care facilities and older family carers wanting assistance in relinquishing care for a person with a disability.

The picture presented paints a scene of duplication and overlap between advocacy agencies, State government service providers and other Commonwealth funded advocacy agencies such as Aged Rights Advocacy Service and Welfare Rights Centres.

Both business service providers and the disability peak bodies agree that housing comes very high on the list of common topics needing advocacy. This is particularly so if their clients are Aboriginal people or have mental health issues, but overall there is a huge unmet need for housing for the clients of business service providers.

Peak bodies also considered that housing was an issue, but in addition focussed on a lack of access to services more generally for people with disabilities, particularly for those with reduced mental capacity. Issues included conditions in group homes, violence, abuse, and the huge number of unmet needs in the choices and services available. Some business service providers also observed that abuse by accommodation providers and in some instances by the clients' own families can occur. Instances were quoted where clients are denied their medications because members of their families are selling it, and that sometimes the client may not be feeling up to working because they have not been fed.

Other specific issues that are particularly sensitive include topics that are also of concern to the general population for example abortion (particularly relevant are abortions for women with an intellectual disability) surrogacy, same sex relationships etc. Another issue raised was working through the 'maze' of the disability services system itself, and confusions over the complexity of state and federal systems.

The ACT Carers' Association foresaw that services and housing in particular are likely to become increasingly needed by people with disabilities. The point was made that many older parents now taking responsibility for their adult children (who may not have survived in earlier generations) will die within the next few years, leaving their adult child without support.

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Consultation with a Community Legal Services Centre foresaw that demand for advocacy for people with disabilities losing their jobs under the new industrial relations legislation would be likely to increase.

9.3 What do advocates actually do? Service provision and advocacy

'It is important to note that many people with disability who are referred to this agency by other service types, do not actually require or seek advocacy services. What they actually need is the original service which they sought (employment, accommodation etc.). In such circumstances, referral to an advocacy agency should not be considered as a positive "outcome" for a referring agency. Additionally such referrals should not always be regarded as evidence of integration and collaboration when they might in reality be evidence of service failure.' (written submission)

During the course of the consultations and receiving written submissions, it became clear that many advocacy agencies that are funded to provide advocacy, also do a whole range of things that are actually the domain of service providers.

Evidence was provided that shows advocates, like business service providers and some peak bodies, spend a considerable amount of time in helping clients get housing or alternative accommodation services, avoiding or extricating them from the criminal justice system, and generally doing the case management work that should, but clearly is not, being provided by the State or Territory departments responsible for human and disability services. In the case of some people with disabilities from culturally and linguistically diverse backgrounds, the advocates also spend an inordinate amount of time in helping them get out of or avoid custody/detention and to negotiate the labyrinths of the Department of Immigration and Multicultural Affairs.

As a written submission from an advocacy agency explains:
'a person who needs to phone Telstra to ask them to disconnect their phone because they cannot afford it. They need someone to make the call for them as they do not have the language skills or the confidence to do it themselves;
a person who has had a car accident and does not know where to go to make an insurance claim. They need someone to go with them to talk with the insurance company about the accident and their claim;
a person who needs to go to court to get a divorce… they need a support person to go with them to court to explain what is happening;
a person who has received a letter from their bank and does not understand it. They need someone to explain to them what the letter says.

These type of situations and the help needed are what used to be called "welfare" and today are usually referred to as "case management" or community services. The service provider needs to become much more involved in the person's everyday life problems. I see this as the role of service providers'.

The above cases are indeed the role of service providers, but in fact these are typical of the sort of work that many advocacy agencies tackle in their day to day work. Another advocacy agency explained:

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> *'The NDAP model should allow for a variety of advocacy approaches across all disability types, but the nature of some disabilities will mean that a specialist approach is needed to meet the specific needs of that particular group of people.*
>
> *For example, people with varying degrees of intellectual disability and autism will always need a specific type of support over the duration of their life. The need for advocacy is not going to disappear when a particular issue is resolved. Rather, the person is going to need continuous support to build confidence, develop appropriate social skills, meet the challenges of 'new people', explore new interests in life, recognise the inherent dangers of community living, and learn to protect oneself from harm.*
>
> *Because of the long-term nature of this support, and the very small gains that may be achieved over an extended period of time, it is almost impossible to adopt an issues-based approach with quantifiable or measurable outcomes and a recognised time of closure.'*

The point is that both advocates and some service providers spend a significant amount of time in doing very good work, but work for which they are not funded.

Much of this seems to depend on the goodwill of the agency and/or the individual worker who takes the necessary action. And evidently it is necessary action, for if it were not taken, the outcomes for the person with a disability these workers are helping could be considerably worse. If we raise the question of why this action is being taken by those who are not funded to do it, it seems very clear that the reason is because no one else it doing it. Basically it comes down to the fact that 'case management' is not being provided by service providers.

It also became clear during the evaluation that many agencies that are not funded to provide advocacy, do indeed provide advocacy.

Some business service providers for example advocate on behalf of their clients, and some advocate for friends and families of their clients. Some people who need advocacy services may approach these service providers, who then try to help them. In some instances, service providers have found that they have become burnt out through trying to help with advocacy issues.

Some service provider agencies that have approached advocacy agencies have been told that the advocacy agency has not time to deal with the issue, and service providers have informed us that unless it's a crisis – and if they tell the agency that the client has an intellectual disability – the advocacy agency cannot help.

Peak bodies also advocate to the extent that they are able, as again, they are not resourced to do so. A typical example is where their members badger the peak body to do something, and so they will take the issue up and advocate by default. All the peak bodies agreed that they are concerned with systemic advocacy issues, but that the demands for individual advocacy work is increasing and in some cases is taking over from the systemic advocacy work they do. Much of this is described as fire-fighting advocacy work.

The point was made that advocacy should be provided by the government, but that it has been passed to the community sector, and operates on a shoestring, with little or no funding for the infrastructure costs because funding is program based. Bidding for program funding is competitive, and sometimes the outputs required are more than the funding can deliver. This is particularly the case where funding would only be sufficient to allow for part time positions, as is often the case.

The question was asked of Business Service agencies of what percentage (if any) of their work would be taken up by advocating. The general consensus was that it would be hard to give an accurate figure, but it would be 'quite a bit'.

One service provider stated the most of the time goes to looking after clients who have the lowest level of disability (mostly mild intellectual disability). This is because these clients can easily 'pass' as 'normal' and hence their behaviour is not recognised as being obviously due to an intellectual disability. This means they are prone to getting into trouble with people who do not know them and who do not recognise their disability. Getting into trouble with the police is a serious though not unusual matter, and at the time of the consultation, the business service provider concerned had two employees in court facing prison sentences. She stated that the service provider helps to pay off fines, because there is no one else to help.

Overall evidence was given that some business service providers spend a considerable amount of time in looking after the best interests of their employees with disability, including advocating for them for the provision of housing or alternative accommodation, getting them out of police prison cells, paying various types of fines for them, dealing with their day to day living issues such as helping them buy their transport tickets, and helping them to access services that should, but clearly are not, being provided by the State or Territory departments responsible for human and disability service delivery. They are also doing some advocacy work that should be provided by the nationally or state-funded advocacy agencies.

9.3.1 Client levels of satisfaction

Most clients who had been supported by advocacy agencies were satisfied with the support they were receiving. This was particularly so among two groups of clients and a family carer group from culturally and linguistically diverse backgrounds, who were overwhelmingly grateful for the help of the agency.

They stated that the staff had gone out of their way to help, being available by telephone on weekends and in the evenings if they thought their clients needed moral support. Transport was also available to clients through the use of volunteer staff, which was a huge help to clients and the family carer group.   One client group felt that if their advocacy agency did not exist they would not have coped, as they all said that they had been at their wits' end.

However some written submissions from people with disabilities were not so positive. One client was not always happy with the service she received, but felt that advocacy agencies have been hamstrung in some areas because they received funding from Government and 'probably need to be careful that they don't bite the hand that feeds them. This puts families and people with disabilities in 'dreadful positions because they

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are unaware of the conflict of interest.' She explained that she had to wait many years before the advocacy agency would help out, because they were locked into helping so many other people.

This client also explained that '*once you have received advocacy for one thing, it doesn't mean that everything is now OK. It is a service that is required to be ongoing. We have needed ongoing advocacy over many years and continue to do so.*'

To summarise, the working relationships between the various bodies and agencies are neither integrated nor coordinated.   Good relationships between service providers and advocates are the exception, and there is no coordination of effort between the FaCSIA funded advocates and the Statutory State bodies which advocate for people with disabilities. Formal arrangements need to be put into place to prevent duplication and overlap and the streamline the advocacy system as a whole (not only those agencies funded under the NDAP).

Common topics raised with advocates are largely around not being able to access services, particularly the most basic human right to accommodation/housing. The provision of basic human services for those with reduced mental capacity is also a major concern and a major topic raised.

Many advocates spend their time doing a range of 'case management' work that is the responsibility of service providers. Business service providers also undertake a range of work which advocate for their employees, as do peak bodies for individuals referred to them.   There seem to be few boundaries drawn between advocacy work and case management work, which has led to agencies feeling morally obliged to take on which for which they are not funded.

It is therefore recommended:

Recommendation 14: That memoranda of understanding, or formal protocols and procedures, are developed with bodies in each State and Territory including but not limited to:

Public Advocates/Public Guardian

Equal Opportunity Commissioner

Disability Commissioner

Complaints Commissioner

State Ombudsman

Recommendation 15: That all governments provide further funding to resource the provision of services to people with disabilities on a case management basis, including intake and referrals to ensure that their issues are addressed and such that advocates do not spend their time on case management work.

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Recommendation 16: That in collaboration with relevant State and Territory bodies, eligibility for advocacy is open to all people with disabilities, no matter whether the issues be those of discrimination, complaints about FaCSIA-funded services, complaints about State or Territory-funded services, abuse and neglect, or based on the person's specific disability.

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10 Standards and Performance

10.1 Standards: Is there justification to develop a set of standards that specifically relates to advocacy services. If so, what should these standards be?

As long ago as 1993, writers were observing it was important that standards which reflected the nature of advocacy and its differences from formal services be developed. They emphasized that the development of standards should be a participatory process, to ensure that people who are knowledgeable about advocacy and people who are engaged in advocacy would be involved, and they suggested that the new standards should be linked with a methodology for evaluation (Cocks and Duffy (1993).

As 'grass roots' advocacy models were favoured at the time, there was little written about measures of performance or key indicators. It was considered sufficient to handle safeguards and accountability issues through holding internal and external reviews, and employing policies to minimize any risk of abuse.

Consultations with FaCSIA managers showed that they all want standards to be developed for NDAP advocacy agencies with three of the eight stating that this is imperative. The majority wanted specific Standards for advocacy included in the current Disability Standards applying to Business Services, with an emphasis on the rights of people with disabilities and their independence. Others wanted a set of guidelines to be developed outside legislation as a set of principles, code of ethics and national guidelines. One wanted the same standards to be introduced for the Complaints Resolution and Referral Service.

State and Territory government managers presented a similar view. The majority agreed that national standards should be developed for advocacy agencies but not necessarily within legislation. It was considered that that might be too constricting and it would be hard to develop while recognising the disparate models within the NDAP. Two advised that they have established their own principles and Queensland has developed a draft set of standards. South Australia reported that a framework model in place requires minimum standards for all State funded disability service agencies. One commented that as the relationship between the Australian Government and the States in regard to advocacy is weak, this has caused the development of advocacy standards to be neglected.

State government managers identified a number of issues to be addressed in any proposed standards. These are:

> Compliance with legislation
> Benchmarks/ KPIs addressing service quality
> Accountability, governance , role of boards of management
> Measurement of client outcomes
> Measurement of client satisfaction
> Effectiveness of intervention/life changes for client
> Accessibility

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Minimum standards of staff training

There was a strong view expressed by the majority in this group that agencies should not be funded for both advocacy and service delivery as this raises an immediate conflict of interest.

So both FaCSIA and State government managers are clear in their support for a set of standards to be developed for NDAP. Indeed some frustration was expressed that this had not previously been addressed. When asked what the standards should be, emphasis was placed upon those relating to meaningful client outcomes.

Detailed descriptions of performance indicators proposed in the Queensland State Government's draft paper are intended to form part of the quality system for the whole Queensland disability sector, and cover performance indicators in the following areas:
    Access to advocacy
    Individual needs
    Decision making and choice
    Privacy, dignity and confidentiality
    Participation and integration
    Valued status
    Complaints and disputes
    Service management
    Protection of legal and human rights and freedom from abuse, assault neglect and exploitation
    Staff support and development

Advocates also agreed that development of standards for advocacy is important but that these should be flexible and not necessarily enshrined in legislation. Principles and guidelines should be developed that give legitimacy to advocacy. This is similar to a recommendation of the 1999 NDAP review, which called for the development of a Code of Practice. They suggested that disability advocacy standards should be developed by a working party established by FaCSIA and be consistent with the current twelve standards under the DDA. They considered Standards 1-9 and 12 are relevant for advocacy agencies and Standard 7 (complaints) could be further developed.

The Aboriginal Disability Network considered that advent of standards that specifically relate to how advocacy services meet the needs of Aboriginal and Torres Strait Islander people with disability would be an asset. This would ensure some way of monitoring and evaluating the cultural competencies of non-indigenous advocacy services.

Several respondents stated that standards would provide consistency across all advocacy agencies and raise the profile of advocates by giving legitimacy and marketability. Thus advocacy would benefit as a profession.

It seemed obvious to disability peak bodies and business service agencies that in consultation with them, standards should be introduced to cover all advocacy agencies. The process for developing and implementing them was seen as paramount, as unless they were fully owned by the agencies rather than being imposed upon them, they were unlikely to be accepted or workable.

However it was pointed out that in some instances, the current standards about client choice could and did lead to problems when dealing with clients with reduced mental capacity. They pointed out that full consideration should be given to the role and practices of advocates where people with disabilities cannot speak for themselves. For business service providers, any standards therefore need to include processes, together with the resources and infrastructure to reach the standards.

Principles and guidelines for advocates might usefully include suggestions such as:

Provide individual advocacy for all people with disabilities who cannot advocate for themselves in order that their rights are upheld

Ensure that information and training or assistance is given to people with disabilities and their families and carers, who have the capacity to advocate for themselves

Advocate for people with disabilities to access services by which they can participate equitably in economic, social and community life

Encourage the families and carers of people with disabilities to understand the rights of people with disabilities

10.2 Quality Assurance: What is the optimum quality management framework to ensure compliance with legislation and funding agreement requirements, while delivering quality advocacy services

Issues of staff training, upskilling, mentoring, lack of opportunities for staff development and significant use of volunteers were mentioned by all FaCSIA Program Managers, who recognised the paucity of resources within advocacy agencies with statements such as:

'*what can they realistically do with few staff and little money*?'

'*.. workers poorly paid, often poorly trained or not at all, work long hours, excessive use of volunteers*'.

They considered that the 5 yearly reviews under Section 14 of the legislation should be conducted by an independent consultant with random interviews with clients other than those selected by the agency. The value of the annual self assessments conducted internally by agencies was also questioned.

Some thought that similar quality management frameworks to those in Business Services should be required and that this would establish standardisation across the sector. Others questioned whether advocacy agencies are clear about what the Australian National Government is asking them to do and thus have difficulties in working out how they will do it. Although there is recognition that some of the larger agencies have quality management strategies, others have not developed basic strategic plans or similar management tools.

Similarly State government managers also questioned whether the Australian National Government has been clear in its expectations of advocacy agencies. They too emphasised the need for proper strategic planning within agencies so that each can be adjudged against the funding agreement.

They considered that a quality framework should reflect standards and be measured against objectives, but also recognised that most NDAP agencies are not at presently resourced adequately to comply with such demands, with staff preferring to attend to client service.

Overall there was agreement between these groups that the development of a quality management framework is required, but at the same time recognition that most advocacy agencies are not sufficiently resourced to neither establish such a system nor comply with the consequent requirements.

While accepting that the current eight key performance indicators in the service agreements are valuable, advocacy agencies wanted much more focus upon client outcomes and client perceptions of service as well as client satisfaction. They felt that exit surveys for all clients should be conducted. However, Citizens Advocacy agencies consider that the model under which they operate has its own quality assurance mechanism, and feel that it is quite appropriate.

Advocates also felt there is a need for funders to recognise that many situations are unable to be resolved, as the preferred service is simply not available. They agreed that the annual self assessments are useful for agency staff and members of Boards but the 5 year audits should be conducted by an independent consultant with access to clients on a random basis - not those selected by the agency.

They stated that there needs to be a much stricter definition of advocacy - for example is answering the phone and giving information advocacy? They also want consistency across agencies with the further development of quality management frameworks and are looking to the Australian National Government to facilitate meaningful discussion.

It was agreed that the quality assurance system for business service providers has made huge differences to the services provided, improving and systemising work practices and referring back to clients.

Some service providers suggested that conditions in other business services can be poor which indicates that much depends on the levels and thoroughness of audits. Peak bodies and business service providers considered that a single quality assurance system, including independent third party accreditation and audit, should be developed jointly in consultation with advocacy agencies.

Some pointed out that this would be even more critical in advocacy than for service providers. They suggested that an ISO-compatible quality assurance system along the lines of the business service system would be beneficial in reducing 'one-off' practices. Some of these stakeholders felt that advocates are driven by passion rather than a systematic and more thoughtful approach.

The service system has been encouraging self-advocacy, and some of the disability peak bodies stated that they support people in building their capacity to articulate what they want, which has lead to an increasing awareness and an increasing voice, in turn leading to the creation of expectations. They agreed that advocacy services are more complex than taking up cases and individual situations and cases are complicated and rarely straightforward.

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However if the services are not there, it is leading to increasing levels and cycles of frustration, resulting in people ultimately becoming threatening and/or turning to the media. Although many people may have no wish to reveal details of their stories publicly, this 'end of the line' approach encourages a focus on individuals and also competition, in that those cases with a high profile attract official reaction and response.

One peak body considered that these things contribute to declining staff morale among advocates who have to deal with increasing levels of frustration. It also leads to a fairly cynical view by advocates of some bureaucrats and politicians who want action in addressing individual high profile issues rather than 'genuinely looking to deal with the underlying conditions'.

Other disability peak bodies also pointed to declining numbers of advocates and declining quality of advocates. One peak body considered that follow-up by advocacy agencies is very poor, leading directly to an increasing prevalence of crisis cases.

An especially notable point emerging from consultations with disability peak bodies is that among agencies, a culture of 'ownership' of a client exists. It is not uncommon for agencies to argue over whose client the person with a disability is, and become very territorial. This quibbling over territorial rights to client ownership is hardly helpful to anyone, especially the client in achieving the best possible outcomes, and can badly impact on working relationships between agencies.

Also governance issues, including staff quality and numbers, resources, systems, training of personnel, were seen as equally important for good results, but inadequate resources often preclude this. Funding for good governance and for staff training has been seen as an 'added luxury' and taking away from the core business of providing direct individual advocacy service to those who need it. However unless the skills, coordination and access (including eligibility criteria) are addressed, it seems unlikely that the system will be producing the best outcomes for clients.

10.3 Training for Advocates

Given the concern about the quality of advocacy under the NDAP, attention needs to be drawn to the training given to advocates.   Although levels of training and professional development were not included in the evaluation brief, and were not specifically raised with advocacy agencies, it plainly appeared from the consultations with other bodies that this was a concern to them.

Ideas on supporting and developing independent advocacy are outlined in a training kit produced by Advocacy 2000. Independent advocacy is discussed and the resource clearly stipulates that the advocate's role is *not* to be impartial, but to be on the side of the person they are supporting - advocates are not expected to 'listen to reason'.

This is clearly contentious. Some bodies raised severe doubts over the reasoning of some advocates and decisions made by them. This was particularly in relation to client choice and the fine line between maintaining a duty of care for any client who is not fully

competent at the time, and representing their wishes and interests to be greatest possible extent.

Professional training[1] should ensure advocates encourage all their clients to understand their responsibilities as well as their rights. It seems entirely counterproductive for advocates to offer their clients the choice *not* to undertake their responsibilities. It is in fact a disservice to clients with reduced intellectual capacity, who have been given encouragement to pay for and validate transport tickets, pay library fines, and generally act responsibly, to be advised by an advocate that they have a choice not to do so, when that means they will get into worse trouble next time. Professional training would also prepare advocates to monitor for abuse and maltreatment by service providers or family members while maintaining working relationships and without necessarily taking an adversarial stance.

Training for relevant personnel in governance issues and basic management skills and techniques would also help increase quality of advocacy service.

10.4 Reporting: What input output and outcome measurements would be appropriate for advocacy services

The 1999 Review of the NDAP recommended that the development of performance indicators and outcome and output measures for advocacy services funded by the Australian National Government be undertaken, in cooperation with advocacy service providers and people with disabilities. However the evaluation has revealed that the current reporting system is unsatisfactory to all concerned.

FaCSIA respondents all considered that much more data needs to be collected, especially data that looks at client service and outcomes. They considered that advocacy agencies should be asked to report on case planning, number of times a client attended, client satisfaction, success or failure of intervention, and resolved cases, so that a national profile of clients can be prepared. They were agreed in expressing their dissatisfaction with the data (basic numbers of existing and new clients and time spent on each) contained in the quarterly reports.

State government managers recognised that measurement tools need to be flexible in order to allow for difference in agencies but emphasised the need for client data measuring perceptions to be collected, including measurement of immediate and long term outcomes, as well as the beginning and ending of intervention. Attention should be given to questions such as:

How has advocacy intervention impacted upon client?
How has advocacy intervention advanced personal plans of clients?

Both groups concentrated discussion upon the need for significantly more data to be collected regarding client perceptions of service and meaningful client outcomes. State

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[1] Nationally accredited training in advocacy for people with disabilities is available. A package developed in 1997 through the Disability Advocacy for Rights and Empowerment as part of a project initiated by Disability Action, was funded by the Commonwealth Department of Health and Family Services. The training is currently being revised and updated by TAFE in South Australia.

government managers considered that reporting requirements should be minimal but should include:

> finance
>
> incoming and outgoing referrals
>
> disability type
>
> identify advocacy issue,
>
> activity reports
>
> minimum data set
>
> staff training initiatives with emphasis upon expressed need/best interest issues

Qualitative inputs and outputs were also emphasised by advocacy agencies and the importance of seeking, recording and reporting client opinions concentrating upon what has changed/ improved for the client and what barriers have prevented successful client outcomes. Advocates felt that strategies for empowering clients should be developed and measured.

Data collection overall needs to be standardised across all agencies funded under NDAP and consistent with similar programs offered by the States and Territories and linked to outcomes. Identifying the time spent on advocacy cases was seen as important.

Advocates understood that funding would be required to improve quality management systems and consequently client outcomes.

There is currently no universal data management system in operation through the NDAP. It seemed quite evident during the consultations and written submissions that advocacy services should be provided with some sort of database software package so that their data collection and hence reporting is uniform. This would of course give a clearer picture of the service being delivered by each organisation and allow for comparisons.

It would also be very useful to the advocacy agencies if such a data base were integrated with a client management system. There is such software available[2].

Reporting requirements that are useful to the advocacy agencies and are useful in informing the funding departments of outcomes and levels of service are clearly urgently needed. Consistency of reporting is currently occurring, but what is being a reported - new and ongoing case and the time spent on them - is of limited value and entails extra work. Information that would be meaningful to the advocates, and help them identify their strengths and weaknesses, gaps in coverage, and all the factors that a proper management information system would give is currently lacking.

That same information, which would be deliverable under an accurate and comprehensive management information system, is also necessary for a rigorous analysis of systemic advocacy needs.

Currently systemic advocacy work is done on an ad hoc basis, through advocacy agencies, disability peak bodies, disability bodies, lobby groups and other organisations

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[2] For example Community Options, Advocacy Management Accounting and Statistical Services, Armidale, NSW have developed a software package which allows the creation of detailed client records, to which can be added individual issues and issue notes, which form the basis of statistical information for reporting

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which represent various interests across the disability field. During the consultations anecdotal evidence indicated that those who have the strongest voice are the most likely to influence policy makers. If policy is to be equitable, it needs to be made on a more exact, knowledgeable and evidence-based foundation.

Careful thought should therefore be given to reporting requirements, and the information requested of the advocacy agencies needs to reflect that, as does the manner in which the advocates gather information and report.

It may be useful for the following minimum performance indicators and outcome and output measures to be considered:

> Numbers and types of people or agencies seeking information
> Information provided
> Numbers referred to the service by referrer
> Numbers accepted by gender, age, new or previous clients, cultural background, disability (primary and secondary)
> Presenting issues
> Outcomes and case resolutions
> Time on books
> Time on waiting lists where relevant

10.5 Priorities and Case Closure

All NDAP agencies are required to have priory and case closure policies and they are shown in quarterly reports and discussed at the time of 5 year audits.

Both FaCSIA and State managers stated that caseloads are too high and agencies are crisis driven with no time to educate clients or provide support in self-advocacy. Doubt was expressed in both groups as to whether advocacy agencies really manage prioritisation or case closure issues adequately. They said that agencies struggle with prioritisation as it is hard to determine the neediest. Cases are generally dealt with on a basis of urgency and that generally referrals were made to other agencies as necessary. Agencies are closing their books because they are overwhelmed.

Both groups reported that agencies struggle with case closure and suggested that there is ample evidence that clients are kept on the agency books with no specific advocacy issue but getting ongoing friendship and support through self help groups. Case closure is problematic because clients often move from one crisis to another with advocates ending up as case managers for the most difficult clients.

This confusion concerning the proper role of advocates is concerning and reflects both the inadequacy of services for people with disabilities and the lack of clarity about the proper role of advocates.

Consultations and written submissions from advocacy agencies show lack of consistency. Some agencies prioritise according to need with an assessment of ability to self-advocate being taken into account. Others appear to have developed a triage system according to urgency with issues such as homelessness and court appearances having priority. One submission illustrates this well:

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> *'A key question at intake is whether there are any critical dates such as court hearings, and we use this as one of the tests for priority. Others include risk of losing housing, risk of committing or being the victim of a crime, extent of other social supports, health status...''*

One agency said that the squeaky wheel principle applied with the most vocal clients getting to the top of the queue. Others said that the prospect of success was a factor in making a decision to assist a client.

Advocates agreed that referral to another specialist agency was often imperative but that many agencies have closed their books so that clients had to wait for weeks or months before they could see an advocate. Very few of the agencies consulted have formal waiting lists.   As one agency wrote:

> *'Our approach is very task focused, however our average client has at least three issues, and most are not resolved quickly. Many clients return to the service repeatedly because their situation of behaviours lend themselves to chronic difficulties.'*

Citizen's Advocacy agencies do not close cases as a general rule, as they aim to provide the client with life long friendship and support.

One of the agencies made the point that the issue that this evaluation should be investigating is not whether advocacy organisations have case closure strategies or related policies, but why advocacy cases cannot be closed. In many instances, the inability to successfully close cases was seen as directly related to lack of funding and/or services provided by government.

Similarly several of the disability peak bodies undertake individual advocacy, as perhaps would not be expected given that much of their work is systemic advocacy, few have procedures for priority and case closure. Rather they take up issues for individuals as they come along, largely due to the gaps in advocacy that is available. The same is true for business service providers.

10.6 Quality Assurance and Complaints

All advocacy agencies reported having grievance procedures to address complaints against them in place. They also give clients an option to be referred to other agencies or an outside mediator (stated to be an overly expensive option for most) or to the Complaints Resolution and Referral Service. However the advocacy agencies stated that this latter option is mostly unsatisfactory as client are then referred on to another service, an option that may already have been offered.

Advocates had very little knowledge of the workings of the National Abuse and Neglect hotline or whether clients accessed this service.

The system required under quality assurance for business services providers includes a requirement that all clients are made aware of the both Complaints Resolution and Referral Service and the National Abuse and Neglect hotline.

Also included under the accreditation system are procedures that clients can follow, including going to a supervisor or the supervisor's manager, and so on up through the levels of the organisation. In most instances clients are required to put complaints in writing, but some complaints handbooks for clients are simple and make use of pictures which clients can use. Generally business service providers are satisfied that clients understand their rights to make complaints. However there are indications from consultations with clients, particularly those with an intellectual disability, that they are sometimes hesitant about complaining about serious matters. Some of the advocates also indicated their experience of service provider staff actively discouraging clients to complain so that client issues are not addressed, and that some clients suffer abuse from members of their families.

Although they do not undertake advocacy, both the Complaints Resolution and Referral Service and the Disability Neglect and Abuse Hotline are operated and managed by one of the larger advocacy agencies. Currently if a complaint is made against this agency, it is handled directly by FaCSIA. However the question of potential conflict was raised by six advocacy agencies through written submissions expressing the view that this work should be taken on by a fully independent body. Given that the question of independence is so central to the operation of advocacy, they considered that any arrangement by which an agency may investigate a complaint against a competitor is unsatisfactory.

Since on a number of different occasions a number of different groups raised the question of a national advocacy helpline, it would be logical to consider consolidating the Neglect and Abuse hotline with a central referral line for those who need an advocate. We understand that both the CRRS and hotline initiatives are to be reviewed separately. However as both are essentially concerned with the rights of people with disabilities, it is suggested that both should sit within the advocacy framework rather than the disability sector.

In summary the consultations and submissions have shown that quality of advocacy is clearly a concern.

The impression gained is that agencies have difficulty in prioritising in a systematic way and that there is a range of strategies used across the sector. The most common strategy taken, given the number of clients needing help and the low levels of resources in the advocacy agencies, is to give priority to the most urgent cases. More often than not, these are time driven by others – a court appearance the next day, an electricity supply that has been cut off and other such emergencies, so that the advocates often deal with one disaster after another.

Setting priorities is something of a luxury for advocates who are routinely presented with time-driven crises. Advocates often have clients who lurch from one crisis to another, and need ongoing support which the advocates provide by default. The view across the sector is that levels of emergency determine levels of prioritisation.

In regard to case closure, some cases might be closed but reopened almost immediately when the client presents with another issue. Paucity of appropriate services means that the client may remain on the books while a lengthy search is made. Other clients should be referred on but no one will accept the client and hence the advocate becomes the de

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facto case manager. Some agencies, particularly those in the citizen's advocacy network, are not geared to case closure but are designed to develop ongoing relationships which may continue for a lifetime. In circumstances when advocacy is perceived as having a friend for life, case closure is rather meaningless.

Logically the question of quality assurance depends on what service is being offered, and until the objectives of the NDAP are clarified and until advocates cease carrying out routine case management which should be done by others, advocacy quantity and probably quality is almost bound to suffer.

Standards under the Disability Discrimination Act do not directly relate to advocacy, and there are no principles or guidelines under which advocacy agencies operate. The proper role of advocates is not clear, and this, compounded by lack of appropriate training and professional development of advocates has led to considerable variation in the quality of the service. Clear standards need to be developed along the lines of the disability standards but to specifically include advocacy work, preferably in the form of guidelines for advocates that can be easily updated.

Data contained in the required reports from advocacy agencies are inadequate for all concerned and need to include more relevant and appropriate data, which can also inform regional and national trends and systemic issues. But again, until the objectives of the program are agreed and established and hence all concerned are agreed and *very clear about what constitutes individual advocacy*, national performance indicators will not be relevant to them all. Useful reports would include the issues and the outcomes for clients if they are to judge performance. The current indicators of numbers of existing and new clients and the time taken on each is hardly an indication of anything other than the number of people who have made a phone inquiry or come into the office. Software is available for reporting on various performance indicators, which also links up with a client data management system.

Consultations raised the issue that quality standards should also include training for all advocates and nationally accredited training has been available for several years. Professional development should not be considered an 'extra bonus' and in the context of a national program should form part and parcel of quality assurance.

The extent to which the CRRS contributes to quality of advocacy services is unclear, but advocates do not find the service satisfactory.

A quality assurance system based on rights, not on disability, that gives clear principles guidelines, including what is and is not advocacy is required, and this needs to be communicated to advocates as an integral part of their training.

It is therefore recommended:

> **Recommendation 17: That clear advocacy guidelines be developed setting out standards, including good governance, training required of advocates and the proper role of an advocate, and disseminated to advocacy agencies.**

Recommendation 18: That advocates be adequately trained in their role and all training includes a focus on the rights and the responsibilities of their clients, proper negotiating of differences rather than taking an adversarial approach, and the duty of care to their clients while acting in their best interests.

Recommendation 19: That in consultation with stakeholders the Australian Government introduce a uniform reporting system, preferably linked to a client management system, that gives measurable and useful information to both the agency and funders, identifies major issues for clients, and through which systemic advocacy and hence policy development can be informed.

Recommendation 20: That a review of the National Disability Abuse and Neglect hotline and Complaints Resolution and Referral Service should give full consideration to transferring the work to a fully independent body within the framework of rights-based advocacy and combining the hotline with an advocacy referral helpline.

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11 National and International Models of Advocacy: service provision or agents of social change?

Internationally there is a myriad of different forms and styles of advocacy for people with disabilities. They include independent advocacy projects and mediation, legal advocacy, general campaign groups, social care organisations, advice and representation projects, and campaigns for disabled people (Advocacy 2000).

Some international literature also makes a distinction between 'do-it-yourself' advocacy, where the person or group represent themselves or those in a similar situation, and 'outsider' advocacy where an external person takes on the representation (cf Comhairle, 2003). A different form of analysis suggests that models of advocacy depend largely on whether advocacy itself should be perceived as a service provided to people with disabilities or as part of a movement for social change. In many ways, this ties in with the distinction between individual and systemic advocacy already discussed.

Overall the models have been identified in the international literature as overlapping and not mutually exclusive (cf Woods, 2003). They include:

Self advocacy: The origins of self-advocacy arose during the late 1960s in Sweden and the United states (Dowse, 2001), and many self-advocacy groups have now been in operation over the years.

Self-advocacy is the practice used to speak up for oneself and has been particularly encouraged for those with intellectual disabilities (termed 'learning difficulties' in the UK literature) as part of the process of becoming included in society. Self-advocacy is now well established in many countries, largely in the context of the closure of segregated institutions and the drive to include people with disabilities into 'the community'.

In Britain, Japan and parts of Europe it emphasises the autonomy of the individual and is often run with an 'advisor' and in conjunction with peer-advocacy groups in the case of users of mental health services. In many ways self-advocacy has been seen as a compelling model which gives great empowerment to the most vulnerable members of society.

However several years on, Priestley (1999) and others, (Barnes & Mercer, 1996; Oliver, 1996a; Kesterbzum 1996) have since argued that the change in policy has not in fact achieved a great deal for the people it was designed to serve. Moreover, the extent to which self- advocacy ensures that people with intellectual disabilities can in fact be heard is questioned.

One of the central points is that a broad collective identify may operate at a cultural level, but to '*operate in mobilization, individuals must make it part of their personal identity*' (Dowse, 2001). The extent to which the 'social model' of disability, which sees disability as a form of social oppression – allows for difference between disabled people is limited, and it seems to be inappropriate for both the theory and the practice of self-advocacy for those with intellectual disabilities.

Critics of self advocacy model for those with reduced mental capacity maintain it may place vulnerable people in situations of greatly increased risk, without adequate support from advocates and other allies. Further, it is argued that such models do not result in much meaningful advocacy, but primarily provide people with disabilities with development of skills, the support of other people who share similar life experiences a source of recreation and/or a friendship network. Each of these functions is very important but does not constitute advocacy.

Further recent research in Japan, which has largely followed the United States model, indicates that while self advocacy may offer one of the most effective methods to empower people with intellectual disabilities, the advisors to some such groups have an overwhelming influence on group decisions. A fine line has to be drawn between genuine self advocacy and *'forcing responsibilities on self advocates, which becomes another form of oppression'* (Tsdua and Smith 2004).

However in Australia self advocacy has not been identified as a major focus for people with reduced mental capacity.

There are several resources available for others who need assistance with self-advocacy. One of these, produced by the Ethnic Disability Advocacy Centre in Western Australia is a manual and accompanying CD which gives a step by step guide for people with a disability from a culturally and linguistically diverse background.   Other work on the development of advocacy skills for people with disabilities has been actively encouraged.

A project on Disability Advocacy and Information reform undertaken through the New South Wales Department of Ageing, Disability and Home Care pointed to the importance of support for people to speak for themselves. In 2002 one-off funding was provided to specialist training organizations and TAFEs to develop and run training workshops on advocacy and other related skills, in regional locations within NSW.   The Victorian government has recently established a Self Advocacy Resource Unit within the Department of Human Services. Advocacy development there has focused on teaching people to speak up, as well as strengthen the capacity of informal advocacy within communities.

Citizen advocacy refers to the long term partnership or friendship with vulnerable people, who often have disabilities and is usually run through volunteers. It has grown to an international model and in some countries is most developed among people living in institutions.

One influential Australian writer feels that advocacy should never be seen as a service, and hence any 'service provision' model is unacceptable. Over a decade ago, it was recommended that the essential elements of advocacy proposed by Wolfensberger (1977) should be adopted in South Australia (Cross, 1992). This has eleven characteristics and is the basis on which the citizen advocacy model is founded:
    1. Separation from case work and other direct services
    2. Individualisation of provisions
    3. Potential for long term continuity of personal relationships
    4. Instrumental, expressive and combined support options
    5. Both formal and informal relationship options
    6. Forms that are highly flexible and easily changeable over time
    7. A built-in ideological orientation and commitment to the advocacy function

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8. Consistency with cultural values
9. Maximally feasible freedom from conflict of interest
10. Practical and feasible in implementation
11. Available as needed

Citizen advocacy in Australia actively seeks out those with a disability and in particular those with an intellectual disability. The model 'matches them up' with a resourceful and principled citizen, who is free from conflict of interest who makes a personal, voluntary commitment to the person to provide some of the emotional and or practical supports required. These citizen advocates are orientated and supported over the long term by the program.   Many of these one on one advocacy relationships endure over many years.

Professional or personal advocacy employs trained workers to resolve a specific short term problem. This can also include legal advocacy where professionals with legal training advocate for people with disabilities through the legal system, and in some countries where people accessing hospital services can be helped in dealings with hospitals.

Public policy advocacy (broadly equivalent to systemic advocacy or lobbying in Australia) that communicates directly with decision makers regarding public policies that influence people with disabilities. It has been described as the most traditional form of advocacy and a logical continuation of providing services on the ground (Woods, 2003).

Local Models and the importance of independence. It has long been maintained that models of advocacy that consist of informal networks and independent groups produce the best results. Much of the literature is concerned with the fundamental question of conflict of interest, and hence the strong argument for independence among disability advocacy organizations.

Early suggestions include models that have a membership base. For example an Australian commentator goes so far as to maintain that an independent membership ensures a separation between advocacy and client services, with fully independent members of Boards and staff. This means neither board members nor staff should sit on government or service committees relating to people with disabilities, they should hold no formal positions within government or service agencies, and are not members of a professional group that has a major role in providing services to people with disabilities. Independence is seen as central.

'the important issue for advocacy groups to address is how the group can prevent itself being co-opted into the service system and at the same time influence that system and the wider society.' (Cross 1992: 25)

Fundamental to the local informal model is the development of relationships and networks among advocacy agencies. There is seen to be great merit in the development of 'informal collectives' of people who share roles and responsibilities, thereby avoiding the pitfalls of pyramid structures with memberships at the bottom, then staff, Boards and a president at the top.   It is assumed that such small groups have strength and effectiveness, but it is not clear how issues such as evaluation of the quality of advocacy

provided, gaps in coverage or duplication of services or the provision of funding would be addressed in this 'informal collective' model.

A similar emphasis on local community advocacy models is contained in the World Health Organisation's discussion of the role of different groups in advocacy. Here the groups considered as advocacy groups are firstly consumers and families, secondly nongovernmental organizations and thirdly general and mental health workers. There is no advocacy role envisaged for governments, although policy makers and planners have an indirect role a role in supporting the advocacy groups. It is clear from this World Health Organisation model that government departments should play no direct part in disability advocacy.

It is assumed that local Ministries of Health would take responsibility and hence have a direct conflict of interest as both service provider and advocate. However, there remains the possibility that the executive branch of government, legislature and other sectors outside health can play an indirect role in advocacy (WHO 2003:21).

Both Canada and UK have taken up keeping the government role at arm's length, although in both international models, government and advocacy sectors have engaged in strong communications.

Principles drawn up between the Canadian government and not for profit sectors are based on interdependence and cooperation; the voluntary sector's unique role; dialogue; collaboration and public accountability (Government of Canada 1999). Similarly compacts between the government and not for profit sector have been drawn up in the UK, to provide a framework that builds and sustains equal and effective partnerships between the two (Joseph Rowntree Foundation 2001).

This is a very different model on which the Australian NDAP is based, which tends to see the provision of advocacy through agencies as the service provision arms of government. However the advocacy agencies themselves see themselves as having a broader and democratic purpose (Kokocinski 2001).

It is clear that the difference between an 'advocacy service provision' model and one in which advocates act as agents for social change echoes the dichotomy of individual-systemic advocacy. The system set up under legislation in 1994 in New Zealand takes both forms into account.

11.1 How well does the NDAP compare to similar programs in other countries or those funded by State governments?

11.1.1 The New Zealand Model of Advocacy

The New Zealand model has long been considered a useful model in considering a revised advocacy system (cf Yeatman, 1996) but despite recommendations has not been used as the basis for reform in Australia. It is essentially a centralized independent system with a Health and Disability Consumer Advocacy agency operated under legislation and through a Health and Disability Commissioner. The agency has a clear focus on the rights of people with disabilities.

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It exists to help advance individual rights, help ensure that the public and service providers are aware of the rights of consumers with disabilities and help ensure any breach of the rights is quickly resolved.

The model provides for substantial linkages between individual advocacy and a national information system. Information collected on a national basis includes standardized data on client profiles, the matters raised, actions taken and the outcomes of the advocacy provided. This can in turn be used to identify trends and systemic failures that need to be explored and provide a firm factual basis in which research can be undertaken to inform policy.

Hence systemic advocacy is informed and can be driven by individual advocacy work at the local level in a rigorous and systematic way with decisions at national policy level made on the basis of evidence rather than reliance on powerful lobby groups.

A report by the Australian Law Reform Commission (1996) explored a similar model of advocacy to the New Zealand model, and proposed that the responsibility should be transferred to a central agency with full independence from service provision. This recommendation was considered as a basis for the NDAP by the 1999 Review Steering Committee, but was rejected on the grounds that the costs could be substantial (FaCSIA 199: 32).

11.1.2 Advocacy in the United States

Many of the US advocacy entities have been in existence for over 25 years, which has resulted in a general depth of experience in advocacy work across fifty or more states. The presence of strong local, state regional and national networks of advocates and good base-level social statistics derived from the organizations give an indication of the levels of well being of people with disabilities (Kendall, 2001a).

Further, the U.S. advocacy sector has been able to forge alliances across a broad spectrum of political and ideological perspectives. It receives funding not only from governments but also grants from foundations, corporate contributions, state and national fundraising, statutory allocation etc, such that the sheer scale and diversity of these is worthy of note. Americans have come to expect organized advocacy for people with disabilities and approve of advocacy as a social institution.

Given the US 'culture of learning', targeted special training initiatives on various needs have been put into place as they have arisen. What is remarkable about this almost routine investment in learning and education is that it is so built in that it escapes observation as being the overall systemic advantage that it is.

Kendall argues that it is hard to imagine another nation with such a developed advocacy 'infrastructure', with routine presence of advocacy in the preparation of legislation, conduct of legal processes, management of services, access to media etc. The success of the advocacy community in establishing and expanding the enforcement of a right to inclusive education is an example of this infrastructure, with people with disabilities, families, legal advocates, dissent professionals and advocacy organization each contributing to the successful outcome, but from quite different bases.

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On the less positive side, Kendall points to the limited resources of enough independent funding for advocacy, together with a reliance on professional paid advocacy provision, such that ordinary citizens may believe advocacy should be only undertaken by a societal authority. Another issue is the level of quality of advocacy services, which at the time of writing had not been the subject of any major national initiatives, and the effectiveness of advocacy priorities, lacking as in Australia, a cogent overall theory to guide them.

But despite decades of the promotion of 'social inclusion' it is striking how little attention has been given to what actually makes the most difference in trying to achieve it. Remaining fixated on trumpeting the goals while leaving the means amorphous, does not for Kendall pass muster as either good theory or a sound guide to social policy.

11.1.3 Advocacy in Europe

A research study undertaken by the European Commission has recently explored models of advocacy for people with intellectual disabilities in Spain, Germany, The Netherlands, England and Sweden (STEPS 2005).

As would be expected, client and family carer involvement and approaches to advocacy vary according to cultural factors and rights traditions. Each country has developed a particular model, such as parent advocacy in Germany, self-advocacy in England and citizen advocacy in Sweden.

The research outlines differences in national systems and arrangements in each of the countries. Most models have access to higher levels, can mount challenges via legal or judicial routes or enjoy variations of an Ombudsman system. At the highest national levels, Ombudsman services and national and European law provides safeguards for protecting and promoting the rights of people with intellectual disabilities. In institutionalized systems, the research indicates that advocacy breaks down the power of administrations and/or service providers and to open them up to public scrutiny.

The research concludes that advocacy needs to operate at both individual levels and systemic levels if power is to be effectively shifted from bureaucratic and professional interest to services users ((STEPS, 2005)

11.1.4 The Canadian Model of Advocacy

In common with many western nations, in Canada the federal Human Rights Commission has responsibility for dealing with individual incidents of discrimination and harassment on the grounds of physical or mental disability, among other things. Provincial legislation, with codes of practice in line with federal legislation is similar to the State and territory disability legislative system in Australia. A formal dispute resolution system operates, with alternatives in the form of mediation, or conciliation before complaints reach the tribunal stage.

The Canadian model also allows for non-profit organisations that represent people with disabilities in a situation similar to Australia. However, like the Australian system, funding for advocacy for people with disabilities comes from a wide range of sources rather than relying on Federal and/or Provincial government departments.

For example, the British Columbia Coalition of People with Disabilities is an umbrella group of individuals and groups of people who use wheelchairs, people with visual or hearing impairments, and people with hidden disabilities, mental health disabilities, learning disabilities and HIV/AIDS. The coalition provides individual and group advocacy for people with disabilities, shares information and self-help skills with people with disabilities and disability organizations, and advocates with government on systemic issues to improve policies and attitudes that affect people with disabilities.

Their key funders are:
> British Columbian Gaming Policy and Enforcement Branch
> British Columbian Ministry of Employment and Income Assistance
> City of Vancouver
> British Columbian Rehab Foundation
> Health Sciences Association of British Columbia
> Human Resources Skills and Development Canada
> Kinsmen Foundation of British Columbia
> The Law Foundation of British Columbia
> Legal Services Society of British Columbia
> Provincial Health Services Authority
> Vancity Savings Credit Union
> Vancouver Coastal Health Authority

One wonders how much time and effort is put into attracting these funds which would otherwise be taken up with advocacy work.

Like their Australian counterparts, Provincial governments vary in their structures, including responsibilities for advocating for people with disabilities.

British Columbia has an Advocate for Service Quality appointed by, and reporting to, the Minister of Children and Family Development. The Advocate does not work directly for the government, but the role is to help adults with developmental disabilities and their families receive good quality services from the Ministry of Children and Family Development, from other ministries, or from service agencies in the community. The Advocate encourages and helps adults to advocate for themselves, but will offer advocacy in a broad range of instances including cases when clients receiving services:
> do not like the services they receive
> feel they are not treated fairly or with respect
> have problems with their social worker, financial aid, or support worker,
> have problems with where they live.

The Canadian Federal Commission also has responsibilities to explore systemic issues and in 2004 created a Proactive Initiatives program to look into systemic issues that have an impact on specific groups.

Consultations and submissions for the evaluation showed that there was little knowledge of overseas programs other than suggestions that some States in the USA, Canada and New Zealand may have models worth considering. There was also minimal knowledge other than vague and anecdotal information about what models may have been developed in other Australian jurisdictions.

However both peak bodies and business service providers consulted raised the need for a coordinated approach that would help to avoid the perceived current *ad hoc* and crisis-driven responses.   This would also reduce duplication and streamline the advocacy system.   They noted that a centralised approach may lead to lack of choice, but at least it would mean that clients would obtain access to advocacy agencies.

11.2 Should the NDAP model allow advocacy services to specialise by disability type?

Consultations with FaCSIA and State and Territory managers showed a convergent view that the emphasis needs to be upon discrimination and rights not specific disabilities. It was argued that advocates need to develop a knowledge base across all disabilities so that they can grasp the big picture and concentrate on rights and inclusion rather than disabilities.   Their emphasis was on the issues, and they thought it important that advocates had the skills to give their clients the required support to access services.

All the smaller States and Territories managers thought that agencies offering advocacy on a disability type are not viable, as the numbers in any one geographical area are too small. One manager stated that specialisation should not be allowed as this created marginalisation and made one disability special and two others questioned the need for specialised agencies for CALD clients, observing that such a policy does not promote inclusion. However, there was some feeling that perhaps some degree of specialisation could be permitted in larger agencies, but overall they all considered that generic advocacy was the better option.

On the other hand, and not unexpectedly, those agencies which represent people with specific disabilities and the Citizen Advocacy agencies thought that specialisation by disability type should be allowed.   Advocacy agencies specialising in advocating for people from culturally and linguistically diverse backgrounds felt that their existence is important enough to warrant their continued specialisation.   As one written submission put it:

> *'Our concern is around the cultural and language barriers to gaining appropriate disability services. We believe strongly that our specialisation in CALD issues and representation of people with disabilities from CALD communities has made a significant impact on how our constituency is serviced by the disability sector. If generalist advocacy agencies were geographically allotted across the state, then a significant level of expertise and skill in working across the axis of disability and ethnicity would suffer... this may also apply to the specialisations within disabilities. Groups with autism may have different needs compared to groups with acquired brain injury''*

However, most advocacy agencies considered that while knowledge of disability types was important, the needs of people with different types of disability and crucially, the issue with which their clients present and services available to them was more important.

Some said that the advocacy system currently has too many gate keepers as it is, and this would add another barrier to access for the client. As most of the advocacy agencies considered that advocacy is about rights, the knowledge about issues and how to go about

getting their clients rights achieved was far more important than detailed knowledge about what their disabilities were.

Many commented that all staff should have good general knowledge about disability issues and in the bigger agencies specialist staff with skills in working with people with particular disabilities could usefully be employed. In the smaller States and Territories advocates considered, like their state funders that specialisation was totally inappropriate because of small numbers and huge areas to be covered.

Disability peak bodies however had mixed feelings about advocacy services specialising by disability types. Some considered that the agencies were too small as things currently stand and often too specialised, which means that clients fall through the gaps. More specialisation would mean small services and more gaps being created, with the likelihood of 'splinter groups' developing, further compounding the issue. Others were less certain and considered specialisation important. However, there was general consensus that advocates need training about the concerns of people with varying types and degrees of disability, in order that the issues facing them are fully appreciated.

Business service providers were largely of the opinion that good knowledge of disability types and an understanding of dual diagnosis (disability and mental health issues) were important, but that essentially advocates need specialisation in issues faced by their clients rather than detailed knowledge of particular disabilities. Of central importance is that advocates are of like mind, and understand and share the values of their clients.

A number of clients considered that the more advocacy groups, the more confused people with disabilities would be.

One client group considered that the current model was adequate, but the system needs considerably more funding to enable it to operate more fully. This client group suggested employing workers with specialised experience in paralegal, health care, Centrelink pensions, housing and immigration areas, and specialist advocates in disability and cultural differences.

However, profoundly deaf people considered that a central specialist advocacy agency with the appropriate funding would be ideal for them, as some of the issues they face are not usually understood by those outside the deaf 'culture'. Low levels of education can mean that an interpreter is not understood by a deaf person, as they may not know the meaning of the words being used. They were however clear that they did not want to be represented by a deaf advocate. Consultations revealed systemic issues facing this group, one of whom for example stated that she was not eligible for jury service on account of her disability, which is an infringement of her civil rights.

The NDAP objectives state that it is important that the views of family and carers of people with disabilities should be included. One family carer argued strongly that advocates should broaden their view and start listening to unpaid family carers. She called for proactive advocacy, forums and affordable conferences to discuss disability services direction. If more open discussion were generated, the needs and dreams and aspirations of the person with the disability/carer would be understood as a way of developing what is wanted in user services, in advocacy. She maintained that policy makers cannot continue to expect unpaid carers to carry 91% of the disability services

load without having a democratic say in the future direction of disability advocacy and policy, particularly when caring for people with decision-making incapacities.

11.3 Delivery alternatives: What alternative delivery models should be considered that would enhance national coverage by the NDAP and at the same time deliver value for money?

There are a number of alternative delivery models in operation currently. The program allows for a range of stand alone, co-located with other agencies, while some are integrated into larger community service agencies and some offer outreach services to other towns/locations.   In this respect, the program is very flexible. This flexibility has occurred partly to meet local requirements but mostly as a result of decisions made on an ad hoc basis over many years.

Several federal managers recommended that services be attached to larger structures sharing resources and infrastructure costs while at the same time providing professional support for advocacy workers. A 'Hub and Spoke' model of service delivery was recommended by half of these managers consulted, with a hub in a local region with outreach service extensions. State program managers agreed with the concerns expressed by their FaCSIA counterparts in regard to small stand-alone advocacy agencies and they expressed a preference for co location in accessible place such as Community Legal Centres or Community Health Centres.

Consultations with State managers also raised issues of lack of disability awareness in regional, rural and remote areas where local communities (including local government) need to be involved in inclusive strategies and become agents of change by building community capacity. Half also raised the importance of systemic advocacy as an agent of change and the need for resources in this area, where individual advocacy is often seen as a 'band aid' measure.

Among the advocacy agencies there is overall dissatisfaction with the current system, particularly from small stand-alone agencies with few staff who are stretched to capacity. Common concerns were expressed about the quality of service provision. Overwhelming support for models with outreach advocacy services was expressed. In addition support for systemic advocacy funding was shown.

Consultations indicate that clients want face to face contact with advocates whom they feel they can trust and who can communicate well with them. They want this contact in a place where they feel safe and where confidential issues will remain confidential.

Telephone contact is often difficult when clients can be overheard, or they feel uncomfortable speaking on the telephone, or indeed they are unable to do so. Although telecommunication systems have been reasonably successful in outlying areas particularly in the health system, it was thought that the systems have limitations particularly with regard to accessing the equipment. Concern was expressed about the cost of such systems. While it was considered that teleconferencing and video conferencing may be appropriate in some situations, such long distance communications is unsuitable for advocacy for those who cannot access the technology and many people with poor communication skills.

A conference organised by the Community Strategies Information Service in May 2006 on the provision of up-to-date information and communication technologies, and attended by the consultants, showed that remote PC communications via dial up and broadband is available. However it remains in its early stages of development and is of poorer quality than standard telecommunications or video conferencing. As such it remains unsuitable for advocacy delivery to many with communication difficulties who may have a PC available.

'Hub and Spoke' models were widely discussed and recommended, particularly in regional, rural and remote areas. An example of this is a model developed in rural Victoria.

As one of the agencies explained this model:
> *'In Victoria this model works extremely well with the parent office in Wodonga receiving all intake enquiries for the advocate based in Benalla. The extension of this type of model in NSW* (and other areas) *would have further benefits given the increased geographic distance which requires coverage. The sustainability of this model comes with the ability of advocates within the parent office being able to share intake rosters and responsibilities. Workers need support, ideas and expertise from each other and operate the system within a strongly supported team based environment. Quality of service is maintained by the Manager who provides supervision to all advocates within the service and is abreast of all issues that the organisation is dealing with.'*

Other examples of similar flexible models were offered including co-location with other agencies. This was thought to be advantageous as long as advocacy services remained independent and were perceived to be so. Such systems clearly ameliorate many of the problems identified in current arrangements such as duplication of infrastructure costs, lack of staff support and supervision, long and time consuming travel requirements and staff burnout.

Advocacy in the Top End of the Northern Territory based in Darwin is attached to the Community Legal Centre and hence allows for a blend of advocates in one agency. The way in which the advocacy service is delivered means that advocates can learn from each other, give support, enhance their professional development and training and provide for mentoring, while at the same time reducing costs of administration, rent and other outgoings. It was suggested that having all advocacy services in one organisation ie Welfare Rights, Aged Rights Advocacy Service, Disability Advocacy would be a good model of local service delivery.

Another advocacy delivery model currently operating out of Geraldton in Western Australia was raised. The agency is co-located and coordinated through a community centre, which also runs services including Legal Aid, specific services for Aboriginal women, Domestic Violence, crisis centre etc. in an open-plan office arrangement. A full time paid coordinator is employed, who handles general administration, funding and financial administration for all the services including advocacy for people with disabilities.

Under this model, each of the services takes responsibility for handling the crisis centre when those workers are not available. This is done on a roster basis, which varies but is usually around two hours a week to ensure full coverage. This 'cooperative' model of service delivery works well for all the services concerned.

Disability peak bodies and Business Services providers also independently raised the idea mooted earlier of a national helpline number as a point of contact and simple entry point to get a quick response and referral to a local advocacy agency. This would need formal alliances and networks and cross referrals between agencies. A website with a reference service directory giving cross-sectoral information and access was also suggested to increase information and awareness among the advocacy agencies, service providers, and clients and their families/carers.

Aboriginal advocates were concerned that the answer is not to 'mainstream' Aboriginal disability advocacy services because Aboriginal people with disability will simply not access mainstream services in any significant way for a range of reasons. They suggested that the focus should instead be to develop and support mentoring relationships like the one already discussed in Section 9. However, the current review of Disability Advocacy Services for ATSI may reach a differing conclusion.

Clients were asked what sort of model of advocacy service delivery they would prefer to see. Many clients had not considered possibilities other than what currently exists, but one of the culturally and linguistically diverse client groups considered that a one-stop shop for *all* disability services would be 'heaven'.

Another group of clients suggested a model of employing workers with specialised experience in paralegal, health care, Centrelink pensions, housing and immigration areas, and specialist advocates in disability and cultural differences. These largely covered the needs of this particular client group.

In summary, the exploration of several international models shows that they vary considerably. Some are centralised, some are equipped to deal with local situations, some are designed specifically for people with intellectual disability, others have more general applicability. While both North American models attract considerable funding from philanthropic and other institutions to a greater extent than the Australian model, there are some questions over the quality of advocacy services.

On the other hand there appears to be some merit in the European and New Zealand models, for while the former has various approaches according to cultural traditions, at the highest levels they both have a centralised system which is independent from service provision. The New Zealand model provides for a national information system used to identify trends and systemic failures and hence provides measurable data on which policy can be based.

International models with a centralised approach at the higher levels appear to have more consistency, and the added bonus that such an approach allows for the collection of factual data on a national basis.

The consultations and submissions have shown that the disadvantages of having advocacy agencies which specialise by disability type outweigh the advantages. Provided that

advocates have a thorough grasp of the issues facing people with different types of disability and know how to deal with them effectively, generalist advocacy agencies are the preferred model. Larger advocacy agencies could usefully employ some advocates with deeper knowledge of particular disabilities, with other advocates having the ability to call on internal or outside expertise if and when necessary.

It is suggested that an overall centralised and independent structure with localised advocacy service delivery, including outreach based on a 'hub and spoke' model and co-located with other relevant organisations, would provide the best of both worlds.

Such a model could be administered, managed and supported by a centre in each capital city, with responsibility for analysis of data from each of the regional hubs within its State or Territory. This would allow for the issues faced by clients to be properly researched and recorded, State or Territory-wide trends to be identified and would inform systemic advocacy at the State or Territory level. In collaboration with other States and Territory centres, this evidence-based research could then inform policy development at national level.

Each centre would support advocates by ensuring they are adequately equipped to undertake their proper role including training clients to advocate for themselves where appropriate. The centres would manage protocols and procedures for collaborative work between agencies within the NDAP and other statutory and non statutory advocacy and would ensure that regional hubs work in collaboration and cooperation with other advocacy services. The centres would not undertake individual advocacy work, but would act as a management and administrative support centre to advocates located in regional 'hubs' and their 'spokes'.

Under this model, regional hubs would take responsibility for individual but not systemic advocacy in collaboration with other advocacy services through protocols developed through their centre. They would take responsibility for maintenance of the appropriate standards of performance and governance, training and professional development of advocates and, in collaboration with their centre, future planning, and day to day management of advocacy services in their region.

They might be located in a metropolitan area or areas, as well as in major regional areas, and would report to their State or Territory centre. Regional hubs would be co-located with other advocacy services, such as a Community Legal Centre or similar agencies.

Reporting to regional hubs under such a model, the 'spokes' which would include any outreach advocacy services, would also undertake individual advocacy, and training in self advocacy where appropriate. They may be located in more outlying areas, and would best be co-located with other community services.

A graphic description of such a model is given below.

A ' Hub and Spoke' Model of Service Delivery

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                    ┌─────────────────────────┐
                    │   Australian            │
                    │   Government            │
                    │                         │
                    │   Attorney-General's    │
                    │   Department            │
                    └───────────┬─────────────┘
        ┌───────────────────────┼───────────────────────┐
┌───────────────┐   ┌───────────────────┐   ┌───────────────────┐
│ Capital City  │   │ Capital City      │   │ Capital City      │
│ Centre 'A'    │   │ Centre 'B'        │   │ Centre 'C'        │
│ Administration,│  │                   │   │                   │
│ management &  │   │                   │   │                   │
│ support to    │   │                   │   │                   │
│ advocates;    │   │                   │   │                   │
│ identification│   │                   │   │                   │
│ of systemic   │   │                   │   │                   │
│ trends        │   │                   │   │                   │
└───────┬───────┘   └───────────────────┘   └───────────────────┘
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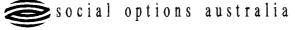Capital City Centre 'A' — Administration, management & support to advocates; identification of systemic trends

Capital City Centre 'B'

Capital City Centre 'C'

Regional Hub 'A1' — eg Metro Region

Regional Hub 'A2' — eg Southern Region

Regional Hub 'A3' — eg Northern Region Provision of individual advocacy, staff development, co-located with other advocacy services, collaboration with other agencies, reports to Centre

Spoke 'A3:1' — Local and/or outreach agency: Provision of advocacy, self advocacy training reports to regional hub. Co-located with similar services

Spoke 'A3:2' — Local and/or outreach advocacy agency

Spoke 'A3:3' — Local and/or outreach advocacy agency

Spoke 'A3:4' — Local and/or outreach advocacy agency

Spoke 'A3:5' — Local and/or outreach advocacy agency

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It is therefore recommended

Recommendation 21:   That agencies tendering for funding be required to offer disability advocacy services on a generic basis, with opportunities to employ/utilise staff with knowledge and expertise in specific disabilities as required.

Recommendation 22:   That the Australian Government establish a disability advocacy centre in each capital city, preferably co-located with other federally funded advocacy services such as Welfare Rights Centre, Aged Rights Advocacy Service or the Ombudsman's office.

**Recommendation 23: That each capital city centre accept responsibility for:
administering, managing and supporting the advocacy service in their State or Territory
undertaking evidence-based research and analysis of reports from their regional hubs (including reports from the local agencies) and hence identify service needs and systemic issues that need to be addressed
ensuring that training for advocates (both paid and voluntary) be based upon National Workplace IV accredited advocacy training program and that this be the standard qualification for all advocates working in agencies funded through the program.**

Recommendation 24: That the model for advocacy agencies in the regions be on a 'Hub and Spoke' model, with regional hubs responsible to the centres located in the capital cities, with outreach or local advocacy agencies responsible to their regional hub.

**Recommendation 25: That the preferred model for delivery of advocacy services for people with disabilities within the regions be co-located within larger service agencies such as
Community Legal Centres
Community Health Centres
Other Community Centres**

Recommendation 26: That outreach models of advocacy service delivery be encouraged in rural and remote areas, locally co-located with other similar services.

Recommendation 27: That where advocacy agencies have a high proportion of ATSI clients and client from a CALD background, staff have a thorough knowledge of cultural differences and the particular issues facing these clients.

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12 Conclusions

The evaluation has uncovered a wide number of areas in which the NDAP is badly in need of reform. This evaluation has explored selected literature on definitions, principles and models of advocacy for people with disabilities, and has researched the current arrangements under which Australian advocates assist people with disabilities.

It has discovered that there are large variations in the types of advocacy available, significant gaps in coverage, poorly understood quality management, wide variations in working relationships in the disability sector, and overall overlap, confusion and a good deal of frustration. What counts as a disability varies considerably and there is such ambiguity over psychiatric disability and mental health issues that some jurisdictions barely recognise psychiatric disability and consider that it belongs in the medical system.

Importantly, many advocates are doing a great deal of routine help and assistance which used to be termed welfare work. This is not advocacy. Conversely many business service providers and peak bodies advocate for people with disabilities. Crucially, there are no guidelines available for advocates, and it seems apparent that many are quite unclear about what they should be doing.

At the heart of this is lies the fact that the Australian system of advocacy has been seen as a disability issue, and rightfully belonging to the Disability Sector. This 'ownership' of advocacy has clouded many of the issues, and has made it difficult for some to recognise that advocacy is about human, civil and legislative rights.

Here we attempt to bring together what has sometimes seemed an impenetrable mass of factors, to answer the twelve key questions.

12.1 The Key questions revisited

Are the existing advocacy services providing adequate coverage for the disability sector?
No. There are large geographic areas of Australia not covered. In addition there are insufficient advocacy services for those most vulnerable, including people with reduced mental capacity and those with communication difficulties

What is the estimated level of any unmet need?
In the absence of any factual data, this is impossible to estimate, but stakeholders consider the level very high.

Should the NDAP model allow advocacy services to specialise by disability type?
No. The emphasis should be on the rights and needs of people with disabilities, not a focus on different types of disability. The special needs of people with particular disabilities need not be based on a specialist advocacy agency model.

Do advocacy services have in place prioritisation strategies and case closure strategies?
No. Advocacy is largely crisis-driven, and some agencies are specifically designed not to reach case closure

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What is the extent to which activities of advocacy services are integrated or coordinated with services provided by other organisations or other government departments?
There is very little evidence that any formal coordination exists. In the absence of planning at State or national level and the numbers of voluntary, statutory and other bodies, there is confusion about who does what among clients and duplication and overlap of work.   Integration with other government departments would compromise independence of advocacy services.

What alternative delivery models should be considered that would enhance national coverage by the NDAP and at the same time deliver value for money?
A 'Hub and Spoke' model of service delivery, with no offices employing less 2.5FTE advocates and .5 FTE administrative staff to ensure quality of service and sustainability. All smaller offices should be co-located and share overhead costs with other appropriate services.

How well does the NDFAP compare to similar programs in other countries or those funded by State governments?
A centralised independent system provides national consistency of quality and opportunity for the collection of factual regional and national data, by which trends and systemic failures can be identified and sound policy developed.

Is there justification to develop a set of standards that specifically relates to advocacy services? If so, what should these standards be?
A set of principles and guidelines would be more useful to the advocates than legislative standards.

What is the optimum quality management framework to ensure compliance with legislation and funding agreement requirements, while delivering quality advocacy services
Both annual assessments and 5 yearly reviews under Section 14 of the DDA should be conducted by independent consultants with interviews with clients other than those selected by the agency. All regional hub offices should develop a strategic plan for their region. Offices should employ sufficient staff to provide quality advocacy services.

What input output and outcome measurements would be appropriate for advocacy services?
A unified system of reporting including:
> Numbers and types of people or agencies seeking information
> Information provided
> Numbers referred to the service by referrer
> Numbers accepted by gender, age, new or previous clients, cultural background, disability (primary and secondary)
> Presenting issues, including issues of access to services by type of service
> Outcomes and case resolutions
> Time on books
> Time on waiting lists where relevant

To what extent does the current level of funding constrain ability to meet the goal and objectives of the NDAP?

The objectives of the program are unrealistic, are not measurable, and need revision to reflect what the program is trying to and can realistically achieve. The current level of funding is considered by all stakeholders as insufficient for effective advocacy provision.

Given that advocacy services are potentially funded from a variety of sources, what would be the optimum basis for their funding?
They should be primarily funded by the Australian National Government and managed by the Australian Attorney General's Department.

12.2 Endnote:

Evaluations of programs usually look backwards and assess how successful the program has been against its objectives. They can examine and compare processes, impacts on specific or general public populations, or at actual outcomes against desired outcomes. Or they can take the form of a review to discover how an overall system works, usually with a view to making it better in one way or another. To a large some extent this evaluation has been a synthesis of each.

It is important for policy makers that they consider not only current but also future needs for people with disabilities and their rights.

The evaluation has shown that the most widespread issue currently needing advocacy is one of the most basic of human needs, housing and accommodation. Consultations indicate that this need is likely to increase in the future. Past policies of deinstitutionalisation of people with disabilities into 'the community' have meant that some have no safe or suitable accommodation options, or if they are lucky they live at home with their family.

Like the population in general, people with disabilities are living years longer than previously, as are their family carers. But longevity does not guarantee care giving, and as family member and parents become frail and eventually die there will be fewer house options for people with disabilities. If the current accommodation situation is bad, the prospects for the next decade or so defy imagination.

The evaluation has shown that lack of other services for people with disabilities is putting a great deal of pressure on advocates to find access to services for clients. Unless service provision increases considerably to those who need it, it is unlikely that advocates will be able to achieve successful outcomes for many of their clients.

Finally, we leave the final word on the evaluation to a submission from a family carer who wrote:
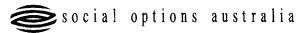
'Advocacy in Australia needs a complete review of goals, outcomes and ways of meeting the needs of the person with the disability/caregivers. This review should be outcome driven, goal driven, service driven and value driven. Somewhere along the way advocacy bodies have become self-serving… A prime example is this current review: it has nothing to do with outcomes for the person/people being advocated for.'

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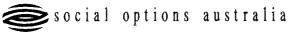|				
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14 Appendices

14.1 Advocacy Agencies and Business Services interviewed

Ability Incorporated
ACROD Tasmania
ACROD Victoria
ACT Disability Aged & Carer Advocacy Service
Action for Community Living
Action for More Independence in Accommodation
Action on Disabilities within Ethnic Communities
Advocacy for Inclusion
Advocacy Eastside
Advocacy North West
Advocacy South West, WA
Advocacy Tasmania
Aged Rights & Disability Team, Top End
Association for Children with Disability
Australian Red Cross (Alice Springs)
Barwon Disability Resource Council
Brain Injury Association of Tasmania
Carers Association ACT
Centacare NSW
Citizen Advocacy Northside
Citizen Advocacy Ryde-Hunters Hill
Citizen Advocacy South Australia Inc.
Citizen Advocacy South Metropolitan, Perth
Citizen Advocacy Perth West
Citizen Advocacy South West Brisbane
Citizen Advocacy Tasmania
Citizen Advocacy Western Region
Commonwealth Rehabilitation Service(Alice Springs)
Community Programs
Disabled Workers Union
Disability Action Inc.
Disability Advocacy and Complaints Service of SA Inc
Disability Advocacy and Information Service
Disability Advocacy Service (Alice Springs)
Disability Rights Victoria
Ethnic Disability Advocacy Centre WA
Family Advocacy (formerly Parent Advocacy)
Greenacres Assocn
Gippsland Disability Resource Council
Grampians Disability Advocacy Association
Headway Victoria
Indigenous Disability Advocacy Service
Independent Advocacy SA
Independent Advocacy Townsville
Individual Advocacy Service, WA

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Kommani
Mental Health Council of Tasmania
Multi Cultural Advocacy Liaison Service of SA
Multicultural Disability Advocacy Association of NSW
North West Advocacy Mt Isa
NPY Women's Council
Parent Advocacy Inc
People with Disabilities WA
Queensland Advocacy Inc
Queensland Parents for People with a Disability
Regional Information Advocacy Council
Rights in Action, Cairns
Self Advocacy Sydney
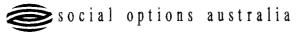Southwest Advocacy Association
Speak Out
Speaking Up for You
Spinal Cord Injuries Australia
Sunshine Coast Citizen Advocacy
Tasmanians with Disabilities
Westernport Speaking Out
Windgap NSW

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14.2 People with Disabilities and Carers Interviewed

Centre	People with Disabilities	Carers
Canberra	6	0
Adelaide	12	0
Sydney	13	2
Melbourne	2	0
Hobart	0	3
Perth	12	4
Alice Springs	0	5
Brisbane	9	0
	54	14

14.3 Peak Agencies interviewed

ACROD
Australian Association for the Deaf
National Association of People Living with HIV/AIDS
Blind Citizens Australia
Women with Disabilities Australia
National Ethnic Disability Alliance

14.4 Individuals Interviewed

Linda Matthews,
EEO Commissioner
South Australia

John Harley
Public Advocate,
SA

Simon O'Brien,
Member of Parliament, WA

Christine Kerr
Acting Chair
National Disability Advisory Council

Pauline Wood
Community Legal Services

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South Australia

Arthur Rogers,
Executive Director, Disability Services,
Department of Human Services, Victoria

Brenda Boland,
Director for Community Development and Support
Department of Human Services, Victoria

Michael Plaister
State Manager, Disability Services
Tasmania

Anne Curtis,
Manager Statewide Operations,
Disability Services
Tasmania

Ingrid Ganley,
Manager, Strategic and Business Support,
Disability Services,
Tasmania

Michele Castagna,
Co-ordinator, Disability Services and Liaison
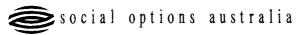Government of Northern Territory,
Alice Springs

Jonathan Walsh,
Senior Planning and Development Officer,
Disability Services
Alice Springs

Brad Swan,
Assistant Director-General
Disability Services Queensland

Peter Mewett
Executive Director Policy Directorate
Disability Services Queensland

Paul Heath
Senior Policy Officer, Strategic Policy Unit
Department of Ageing, Disability and Home Care
NSW

Mary-Jane Clark

Acting Director,
Strategic Development & planning
Department of Ageing, Disability and Home Care
NSW

Alison Crisp,
Senior Manager, Policy & Planning
Department of Ageing, Disability and Home Care
NSW

Pam Jenkins
Manager, Policy & Planning, Sector Development & Support
Department of Disability, Housing and Community Services
Canberra, ACT

Sally Gibson,
Sector Development and Support
Department of Disability, Housing and Community Services
Canberra, ACT

Judy Gallagher
Manager of Individual Development Program
Disability Services Commission,
Department of Health
Western Australia

Judith Chernysh
Senior Policy Officer
Disability Services Commission,
Department of Health
Western Australia

Jacinta Hanrahan,
Senior Policy Officer
Disability Services Commission,
Department of Health
Western Australia

Maurice Corcoran
Disability Services
Department for Families and Communities
South Australia

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14.5 Written Submissions Received

14.5.1 Organisations:

Ability Incorporated
Aboriginal Disability Network
Aboriginal Disability.emp
ACT Disability Aged and Carer Advocacy Service
Action on Disability within Ethnic Communities
Activ Foundation WA
ADAP
Advocacy Eastside
Advocacy for Inclusions ACT
Advocacy Northwest NSW
Association for Children with Disability (Tas)
Australian Association of the Deaf
Australian Parent Advocacy
Autism Aspergers Advocacy Australia
Brain Injury Association of NSW
Brain Injury Network of South Australia
Citizen Advocacy Northside
Citizen Advocacy Perth West
Citizen Advocacy Ryde-Hunters Hill
Citizen Advocacy South Australia
Citizen Advocacy South Metropolitan WA
Citizen Advocacy South West Brisbane
Citizen Advocacy Sunbury & Districts
Citizens Advocacy Inner East Victoria
Communication Project Group
Concerned Individuals and Parents Action on Intellectual
Disability
CRS Alice Springs
DADAC
Disability Advocacy and Complaints Service of South Australia
Disability Advocacy and Information Service
Disability Advocacy Network NSW
Disability Advocacy Service Hunter (DASH)
Disability Justice Advocacy
EDAC
Family Advocacy
Federation of Ethnic Communities Councils of Australia
Gippsland Carers Association
Gippsland Citizen Advocacy
Headway Victoria
IAT Queensland
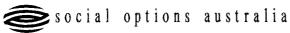Illawarra Citizen Advocacy
Independent Advocacy SA
Indigenous Disability Advocacy Service
Karkana Support Services
MALSSA
MDAA
Mid North Coast Area Disability Committee

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National Carers Coalition
National Ethnic Disability Alliance
Newell Citizen Advocacy
Our Voice SA Committee
Parent Advocacy SA
People with Disabilities
Personal Advocacy Service
Queensland Parents for people with a Disability
Rights in Action
Rights in Action Cairns
Southern Citizen Advocacy
Southwest Advocacy Association
Speak Out Association of Tasmania
Spinal Cord Injuries Australia
Sunshine Coast Citizen Advocacy
Victorian Disability Advocacy Network

14.5.2 Individuals:

Annette Justin
Estelle Shields
Irene Chapman
Mary Walsh
Nell Brown
Stephanie Mortimer