family ADVOCACY

Submission in response to the Productivity Commission Draft Report into Disability Care and Support

Issued by the Australian Government Productivity Commission

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family ADVOCACY

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Foreword

This submission is made in response to the release by the Productivity Commission, in February 2011, of the draft Report – *Disability Care and Support.*

Background

Family Advocacy is a community based, state-wide disability advocacy organisation which promotes and defends the interests, rights and needs of children and adults who have developmental disability in NSW.[1]

The majority of Management Committee members and staff are parents or family members of people with developmental disability.

Family Advocacy is committed to contributing to the dialogue around the development of a national long term care and support scheme and welcomes the Draft Report into Disability Care and Support.

Comments

General

Family Advocacy would like to congratulate the Productivity Commission on its clear draft report into Disability Care and Support. This is the most important public document in Australian disability services for more than 30 years and provides useful analysis and resources to rebut common myths about the most effective way to support people with disability.

This submission seeks to respond to specific information requests identified in the draft report, as well as raising issues of importance to people with disability.

As Family Advocacy sees the provision of independent disability advocacy as a very significant aspect of any support scheme, advocacy has been dealt with as a separate section within this submission.

Specific

Chapter 4

- **Innovative approach to specialist disability housing - pg 4.6**

Family Advocacy welcomes the option to enable people to ‘cash out’ specialist disability housing. The current description in the draft report however, focuses on the value of rent only, whereas support is also critical for many people with disability.

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[1] Developmental disability includes any disability that arises within the developmental period and includes intellectual disability, cerebral palsy, Down Syndrome, spina bifida, autism and multiple disability.

Family Advocacy recommends that the example is reworked in the final report to ensure an understanding that the option of ‘cashing out’ includes the value of support to sustain a lifestyle as well.

- **Higher electricity costs – pg 4.9**

Family Advocacy recommends that existing rebate schemes are transferred to the NDIS and the level of compensation is increased to reflect the full additional costs incurred.

- **Accessible taxis – pg 4.22**

The high cost of accessible taxis means that they are only used by people who are unable to use any other form of transport.

In seeking to limit the cost of taxi subsidies, the Commission is proposing passing on those increased costs to users. Family Advocacy believes that such increases will be counterproductive, potentially forcing some people with disability out of paid employment because the costs of getting to work are not sustainable on the income earned from work.

Family Advocacy recommends that taxi subsidies are in fact increased, so that the disparity between the cost of public transport and the cost of accessible taxis is reduced.

- **Whether Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance and Child Disability Assistance Payment should fall within the scope of NDIS – pg 4.24**

This is a complex issue that may require a staged approach as people gain trust in other changes foreshadowed in the system.

Questions of the different carer payments are dependent on whether family carers, particularly resident family carers, are able to be employed to provide assistance. When that issue is settled is the time to determine whether it is appropriate to bring the carer payment, supplement and allowance into the NDIS.

The Mobility Allowance would be appropriate to be part of the NDIS but in keeping with the general view that the NDIS should meet the reasonable and necessary costs of disability, the mobility aspect of the NDIS should be increased to meet the real costs of travel, particularly where elsewhere in the report, the Commission is seeking to reduce the cost of taxi subsidies.

Child Disability Assistance exists in acknowledgement of the additional costs of raising a child with disability. Given that the NDIS plans to provide reasonable and necessary assistance needed to support the development of and raise a child with disability, it would be appropriate for the payment to fall within the NDIS.

- **Co payment – pg 4.33**

Family Advocacy accepts the role of co-payments with the following provisos:

- that the co-payment can be waived or reduced if a lack of preparedness to pay the $500 means that the vulnerable person misses out on much needed support;

- that the co-payment represents the only additional payment the person is required to make;

- if the person will require supports outside the ambit of the NDIS for which payment is required, this is taken into account in order to waive or reduce the co payment.

Chapter 5

Assessment

Family Advocacy supports the Commission’s view that needs assessment should take a person’s aspirations into account.

Natural supports

Family Advocacy agrees that assessment should take account of informal support provided by family and friends. It is essential however, that there is provision for **rapid** reassessment and supplementation when the level of informal support changes. The success of this provision will depend on the extent to which the level of support can be adjusted urgently when there is a change of circumstances. A long wait for reassessment will teach people to discount informal support in seeking paid support.

Independent professional assessment vs. self assessment

Family Advocacy understands the concerns of the Productivity Commission about having self assessment as the foundation on which the NDIS is based. The demand for self assessment however is based, at least in part, on extensive experience of assessment as a negative, deficit based process in which people are asked demeaning questions to ascertain need and worthiness. The negativity toward professional assessment is strengthened when assessment results are expressed in demeaning descriptors, as for example, with IQ.

Family Advocacy agrees with the Glendinning et al. comment (pg 5.19) that “Having both views (professional and self assessment) was believed to produce a more accurate assessment of needs and offered an opportunity for useful dialogue between the service user and the care coordinator”.

Family Advocacy is pleased to see Figure 5.2, *Suggested assessment process*, begins the process through self assessment, which is then complimented by a professional assessment. We urge that guidance is given to ensure that the professional assessment is framed as:

- a collaborative process (not a testing of capacities or incapacities);
- understanding needs and aspirations;
- asking the question: *“Given your needs, what does it take to achieve your aspirations?”*

Chapter 7

Governance of the NDIS – Underpinning of the UNCRPD

The legislation that establishes the NDIA must make reference to the UNCRPD and ensure that all activities paid for under the NDIS comply with the UNCRPD. This includes the way in which supports are delivered to individuals as well as the governance structures.

➢ Making the system work for people with disability

Family Advocacy is pleased to see the draft report indicates that:

- the case management role of the NDIA should be fashioned on the role of Local Area Coordination in WA. ***Family Advocacy recommends*** that this is further highlighted in the status of a recommendation.

- the NDIA should not be a supplier of services (Putting the fox in charge of the hen house – conflicts of interest. pg 7.7)

- Disability Support Organisations are separate from both the NDIA and service providers, standing beside the person with disability assisting the person to 'get a life'. There appears however, to be some level of contradiction in the discussion of the role of DSOs and service providers throughout the report.

➢ The role of DSOs

The role of DSOs as elaborated in Box 7.2 clearly demonstrates a role of assisting individuals to make decisions based on their best interest. Independence from service provision and the NDIA (ie minimisation of conflict of interest) is paramount.

However, the Overview document (pg 31) states that:

"The functions of disability support organisations and service providers could overlap, but should not be exactly the same. Service providers could act as disability support organisations for services (b) to (f) but could not undertake (a)"

This summary is of concern to Family Advocacy because it causes confusion.

We acknowledge that good person centered service provision begins with information and includes personal planning and capacity building of people with disability. However, specifically assigning to a service provider the role of providing information about the scheme, the assessment process and user's rights and responsibilities, adds confusion and potential conflict of interest, as service providers claim the status of 'standing beside the person' as a result of their assigned role in providing information and planning.

Family Advocacy recommends that the final report provide greater differentiation between the roles of services and DSOs to strengthen the independence of DSOs.

➢ Vouchers – pg 7.11

The Report indicates that a voucher model will be used at the introduction of the NDIS to give certainty in the early stages (which it appears, may be a matter of years).

The NSW *Stronger Together 2* promises people with disability that by 30 June 2014, anyone receiving disability services will have the option of using an individualised and portable funding arrangement, including self directed support. These arrangements are already in place in Victoria.

Family Advocacy recommends that the Final Report confirms that the voucher system will not restrict the level of control people with disability and families already have over their supports, through self directed options already in place.

- **Building the capacity among participants and providers to work within the scheme**

Figure 7.2 “Who does what?” gives the NDIA the responsibility to “help build capacity among participants and providers to work within the scheme”. This is not really discussed further.

Family Advocacy is pleased to see the recognition of this important function and recommends that this is an ongoing function, particularly in relation to participants.

Family Advocacy believes that capacity building for people with disability and families is best undertaken by DSOs, both on an individual basis as well as through seminars that develop vision and empower people to have high expectations and guide their own lives.

Family Advocacy recommends that the NDIA fund DSOs to provide capacity building programs for people with disability and families.

- **Advisory Council to the NDIA Board - pg 7.28**

Family Advocacy is disappointed with the relegation of people with disability to the role of a sub-group, within a larger advisory body for the new NDIA. It is vital that the rhetoric of valuing the expertise that people with disability bring to the design of their own support be supported by creating decision-making roles within the NDIA for people with disability. We accept the arguments about the need for financial, insurance and management expertise, but the business of the NDIS is ultimately about delivering disability supports and this expertise is missing. There also appears to be an assumption that there are no people with disability with expertise in finance, insurance and management. This is incorrect and insulting to people with disability.

In many advisory boards, once all stakeholders are given a vote, the voice of people with disability is drowned out. For example, a number of years ago, a staff member of Family Advocacy was a member of the Taskforce of the Ministerial Council on Employment, Education, Training and Youth Affairs (MCEETYA) tasked with developing disability discrimination standards for education. Once all stakeholder groups were represented, membership was made up of eight government representatives, seven education provider representatives and two representatives of people with disability. The replication of this type of membership would be totally unacceptable. In addition, it is critical that the Advisory body consult widely with people with disability and families to ensure the implementation of the NDIS is consistent with aspirations.

Family Advocacy recommends that representatives of people with disability constitute 50% of the Advisory Board and that the Advisory Board is required to consult with people with disability and their families.

- **Complaints and dispute resolution – pg 7.39**

Family Advocacy understands the necessity to have very clear and strong mechanisms that form the parameters around eligibility for the scheme. What must sit alongside this are equally clear and strong mechanisms that enable those who may not be happy with decision making, that in their view, has disadvantaged them in some way. Therefore, we are of the view that any appeals process must have a strong statutory capacity to overturn decisions and should be external to the body that is responsible for the original decision that is being appealed.

Chapter 8

Approving specialist providers – pg 8.28

Family Advocacy is pleased to see that the NDIA will develop an approval process for service providers and private contractors offering their services. We seek clarification however, in relation to family members or people selected by the person, because they are part of the person's support network.

Family Advocacy believes that under self directed support, the NDIA should offer and pay for approval processes e.g. police checks, but should not require participants to use them. This is already the case in NSW under the Attendant Care Program. Those participants who use Allowance Inc, a financial intermediary, are offered assistance with police checks but participants are not required to have police checks prior to employing an attendant.

Advocacy in the context of the NDIS

Family Advocacy welcomes the draft Report's identification that people with disability will require advocacy within the new landscape created following the implementation of the NDIS. However, mention of advocacy throughout the document is adhoc and confused with other mechanisms, leaving the reader uncertain about the Commission's understanding of the role and function of advocacy on behalf of people with disability.

The report appears to indicate that advocacy would sit within the DSO arrangement. (Overview document, pg 31, third dot point).

- **The need for separation of advocacy from service delivery**

Advocacy must be separate and independent of any disability service system if it is to do its job well.

Advocacy is not service delivery nor is it 'case management'. Service delivery, as understood by the sector, equates to the types of services delivered by disability service providers' i.e. supported accommodation, day programs, community support, respite, therapy, post school programs, employment etc.

Case management is about assisting people to access and negotiate their way through the service system and access pre-existing services (as described above). Advocacy assists a person deal with a particular issue that they are facing.

An advocacy agency performs very different functions depending on the form of advocacy it is conducting. Family Advocacy functions under the social advocacy framework which describes advocacy thus:

> “Speaking, acting or writing with minimal conflict of interest on behalf of the best interests of a person or group to promote, protect and defend their rights and interests as participating and contributing members of the community and achieve inclusion in the life of the community through:
>
> – being on their side and no-one else’s;
>
> – being primarily concerned with fundamental needs;
>
> – remaining loyal and accountable to them in a way that is emphatic and vigorous;
>
> – staying autonomous and separate from direct service provision.

Also, to understand the function of advocacy, it is important to identify what it isn’t.

Advocacy isn’t:

- Direct human service provision *(not on the side of the vulnerable person or group, significantly flawed in terms of meeting fundamental need, accountable to others, and have loyalties to different parties)*

- Government advisory bodies *(accountable to the Minister or Department, not to people with disability)*

- Counseling *(relies on the client to act to resolve a matter, whereby advocacy relies on the party being advocated against to act)*

- Mediation and conciliation *(cannot be on the side of the most vulnerable person and, in fact, in mediation and conciliation, independent advocacy could be needed by the less powerful person - taking sides has no place in mediation. It is therefore not advocacy)*

- Complaints handling *(often located in a human service framework only and often resulting in mediation and conciliation [refer above], mostly short term in nature)*

- Case management *(not on the side of the vulnerable person or group but more an agent of the human service industry)*

- Guardianship *(substitute legal decision-making where people are unable to make decisions themselves due to the nature of their disability; decisions taken are not necessarily concerned with fundamental needs and often people require strong advocacy when others are considering seeking guardianship)*

- Information (in and of itself) *(not on the side of the person or group or primarily concerned with their fundamental needs)*

- Support groups *(not on the side of the vulnerable person or group, not accountable to them, nor particularly vigorous).*

There has been much confusion over the years about the role of advocacy within the disability service provider arena, with providers claiming that they can also deliver advocacy to their ‘clients’. Family Advocacy strongly and vigorously objects to this claim, as a client within a service cannot be independently advocated for, in the true sense of the word, by a staff member whose loyalty and pay cheque is tied to the provider. This is a weak, conflicted and inappropriate response to the true nature of the problem, which is that the Federal and State Governments have never properly funded the Australian advocacy sector to the degree to which there is enough independent advocacy support available to people with disability when they need it.

Family Advocacy strongly recommends against the positioning of advocacy within the DSO framework and suggests the need for a new national statutory advocacy authority (discussed in the next section)

➢ Funding of Advocacy

The current situation, whereby both the Federal and State Governments fund and administer disability advocacy has created a situation whereby advocacy is seen in many instances, to ‘bite the hand that feeds it’. There is also an inherent, inbuilt conflict of interest in a Department funding and running disability services, as well as funding advocacy. This real and perceived conflict of interest has undermined the true strength of the advocacy sector since the implementation of the *Commonwealth Disability Services Act* in 1986.

Adding to this dynamic has been the gross underfunding of Advocacy, which has led to many gaps in the availability and delivery of disability advocacy across the country. It is this circumstance that has led disability service providers down the path of deciding to provide ‘in-house’ advocacy to the people within their services, as there isn’t a large enough advocacy presence within Australia to meet the demand. This response is understandable, but it is not the solution to the need for a much greater availability of independent, disability advocacy being provided to Australians with disability.

The advocacy sector has been lobbying the Federal and State Governments for more funding for at least the past 20 years. It has become clear to those advocacy practitioners and agencies who have been around for most of that time, that the reluctance to grow the sector has stemmed in part from the inability of the Departments that fund and manage the sector, to articulate adequately the worth of the advocacy actions in people’s lives and the necessity for advocacy to grow in proportion to the growth of the disability service system. On a person to person, day to day basis, most advocacy is aimed at the disability service system. The bigger the system, the greater the need for advocacy.

As is demonstrated in Figure 8.3, pg 8.7, *Expenditure share 2008-09*, advocacy funding was measured, along with administration and information services, at less than 4% of the total budget allocated to the CSTDA for that year. Family Advocacy has been lobbying Governments for many years, to consider a minimum of 10% allocation of the global budget to advocacy alone.

Family Advocacy recommends the Commission accepts the proposal put to the Australian Government by Disability Advocacy Network Australia (DANA), in relation to the administration and funding of advocacy http://dana.org.au/wp-content/uploads/Administrative-and-Leadership-Proposal.doc. **Attachment No. 1**

DANA is proposing that a separate Statutory Authority be established for a national independent disability advocacy program that maintains links to Commonwealth and State and disability administration through its Board structure. Family Advocacy supports this proposal.

- **Access to Advocacy**

Family Advocacy has concerns over the Commission's positioning of advocacy within the DSO structure for additional reasons. It would appear that the Commission is proposing that eligible participants of the NDIS would 'pay a fee to DSO's out of their allocated funding plans if they choose to use their services' – *Paying for DSO's* pg 7.16.

Family Advocacy strongly disagrees with any movement towards people having to pay for advocacy out of their individual funding packages.

Family Advocacy recommends that advocacy remains block funded.

The rationale behind our position is that:

- There will be many people with disability who will not be eligible under the NDIS and who will not have a funding package.
- People will need every cent of their package to pay for their support needs.
- There are a significant number of people with disability who currently reside in institutions. These individuals will not be actively seeking advocacy support, but are in fact those most in need of it. Many do not have family members advocating on their behalf, therefore have no advocacy at all. These individuals need to be sought out by advocacy agencies that can then provide the type of advocacy most appropriate to the person and the circumstances at the time.
- There are a number of essential forms of advocacy that can't be paid for out of an individual's funding package i.e. systemic advocacy and advocacy development of family members.
- Advocacy needs to have the capacity to be pro-active as well as reactive i.e. to act as an 'early warning system' to alert people to changes that may impact upon them.

Some other aspects of advocacy activity that must be taken into account are:

- Advocacy will be essential in ensuring that the new system is responsive to the people for whom it is created.
- People may need advocacy in order to understand their right to appeal eligibility or their funding allocation.

- Advocacy will be needed to ensure the NDIS acts with the framework of the UNCRPD.

ATTACHMENT NO. 1

DANA Disability Advocacy Network Australia

A Proposal for
A New Administrative and Leadership Framework For Disability Advocacy

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Disability Advocacy Network Australia (DANA) Ltd

DANA is a Company limited by Guarantee, established in October 2008 and incorporated in May 2009 to
strengthen and support Disability Advocacy Organisations across Australia to advocate for and with people with disabilities so that they are valued and included members of the community, their fundamental needs are met and their human rights are respected.

DANA purposes include:
(a) promoting the role and value of independent advocacy;
(b) providing a collective voice for members;
(c) facilitating communication and information sharing between disability advocacy organisations;
(d) facilitating support and development for members, staff, and volunteers of disability advocacy organisations;
(e) promoting or undertaking relevant research relevant; and
(f) promoting the human rights, fundamental needs and value of people with disabilities;

DANA has 45 member organisations including at least one from each of the States and Territories of Australia. Member organisations engage in systemic, individual, and specialist advocacy provision.

1. Executive Summary

a. Context

Ongoing dissatisfaction with the administrative and funding framework for disability advocacy has given rise to many reviews and reports over the life of the Advocacy Program. Yet there has been little change. DANA believes that this is because the resulting proposals for change either did not properly address the needs of people with disabilities in relation to independent advocacy support or did not go far enough in recognising that a new approach was required.

There is now a window of opportunity to create an innovative and more appropriate administrative and leadership framework for disability advocacy so that the sector can be properly supported to provide quality advocacy to some of our country's most vulnerable citizens. This opportunity arises from the recent establishment of a Disability Advocacy Sector Representative body (DANA), the significant COAG reforms across health, aged care and disability support; the Productivity Commission Inquiry into a National Disability Long-term Care and Support Scheme and the ratification of the UN Convention on the Rights of Persons with Disabilities.

DANA has developed the following proposal after detailed consideration of all the previous reviews and reports and having regard to the variety of views expressed by advocacy organisations in the various States and Territories. Feedback has been sought from DANA members and the broader disability advocacy community as well as from State and Territory government officials.

b. A New Statutory Advocacy Authority

DANA is proposing that a separate Statutory Authority be established for a national independent advocacy program that maintains links through its Board structure to Commonwealth and State and disability administration. Program delivery funding is to initially be that which is made available for independent advocacy for people with disabilities of any age via the National Disability Advocacy Program (NDAP), Home and Community Care Program (HACC) and the State National Disability Agreement (NDA) funded Advocacy programs. Program administration funding would be drawn from the current administration dollars used for these Programs across the country. The Program would be administered in accordance with a set of principles (see full report) that establish the core elements and functions of an independent advocacy program. It would be governed by a Board that includes state and federal officials, representatives of advocacy organisations and people with disabilities and independent advocacy experts.

The functions of the proposed new authority would be as follows:

- Promotion of the value and importance of independent advocacy
- Advocacy sector planning and development including identification of demand and development of comprehensive Program framework incorporating the elements indentified in the Principles above
- Management of core recurrent advocacy funding perhaps via State based officers
- Development and Implementation of a Performance Reporting and Quality Assurance Framework for advocacy providers
- Research in relation to advocacy practice, administration and demand
- Influence Government policy development and implementation in favour of advocacy.

Such an Authority, properly constituted and funded, would, through driving quality improvements to advocacy, also drive a culture of respect for and inclusion of people with disabilities in the life of the community.

c. A Representative Body for Advocacy

DANA proposes that an advocacy sector representative body (DANA) is funded to play a leadership and advocacy role to promote strong and effective independent advocacy.

d. A Funding Commitment for Advocacy

DANA proposes that government make a commitment to provide advocacy funding that responds to the need for independent advocacy and is linked to growth in the incidence of disability in the population and to growth in the level of funding provided for services to people with disability regardless of their age.

e. Moving Forward

In the context of a commitment by Commonwealth and State Ministers in the health, aged care and disability services sectors to program administration reforms, DANA recommends that:

1) **A working group of Commonwealth and State administrators in relevant programs meets with representatives of DANA to discuss this proposal prior to any decisions being taken to realign current funding arrangements for independent advocacy.**
2) **A feasibility study is undertaken to map out the scope of the DANA proposal for a separate statutory authority and a timeframe for implementation. This should also include the possibility of an interim administrative structure while appropriate steps are taken to establish a new administrative framework.**
3) **All jurisdictions cooperate in identifying the funding in their current programs that might best sit within an independent advocacy program. This includes both funding to agencies for advocacy support as well as administration funding.**
4) **Government recognise DANA as the representative body for the independent disability advocacy sector and provide it with interim secretariat funding pending finalisation of the Review of the Disability Secretariat Program.**
5) **Government commit to progressively moving towards a level of funding for advocacy that responds to the unmet need for independent advocacy.**

2. The Right Time for Change

a. Introduction

DANA has identified that there is a critical need to develop a more coherent approach to resourcing and administering independent advocacy across the nation. Currently, the independent disability advocacy sector is funded through multiple programs for people with disabilities across the lifespan. This funding comes from different state and commonwealth jurisdictions as well as from different program areas (disability, mental health, aged care, HACC, Attorney Generals). Given the low levels of funding and the need to ensure distribution across all regions of Australia to locally managed advocacy agencies, this complexity creates inefficiencies in both program administration and program delivery. Agencies with multiple funding currently have to audit, acquit and administer data collection in different ways.

The administration of advocacy within departments that also administer much larger service provision programs leads to administration, standards frameworks and funding acquittal requirements that are better suited to service delivery agencies but less well suited to the provision of advocacy support.

We have therefore developed:

- A proposal to safeguard the independence and resource base of independent disability advocacy.
- A rationale for the ongoing development of disability advocacy program resourcing.
- A mechanism for strengthening and supporting the growth and development of disability advocacy

The proposals developed identify and respond to a set of principles that provide the key to the provision of a coherent advocacy program for people with disability across Australia. These principles have been derived from the many submissions made by advocacy agencies to the multitude of reviews and reform processes undertaken over the years. They have been debated and discussed in a wide variety of advocacy agency forums and review consultation processes and are broadly agreed across the disability advocacy sector.

b. COAG Reform Environment

The current Commonwealth Government has recently announced major reforms to the administration and management of health care, acute care and community care for people with disabilities and frail older people.

Reform of the administration and management of disability advocacy funding is also under consideration. This provides an opportunity to create a new administrative framework that incorporates existing disability advocacy funding arrangements administered by Commonwealth, State and Territory governments and under a variety of programs including the National Disability Advocacy Program, the Home and Community Care Program, the National Disability Agreement, the Disability Discrimination Legal Services Program and the National Aged Care Advocacy Program.

In particular the recently announced reforms to the Home and Community Care Program require that immediate attention is given to the future of the advocacy component of this Program.

c. Advocacy Reform on the Agenda

Since the 1991 Commonwealth State and Territory Disability Agreement (CSTDA), responsibility for the funding and administration of advocacy has been split between Commonwealth and State and Territory governments. The Commonwealth Government has undertaken its advocacy responsibilities through the National Disability Advocacy Program. State and Territory Governments have taken differing approaches to the provision of advocacy funding. This has led to the defunding of advocacy in some states and to advocacy being delivered by providers of disability services in others. Some states do not fund individual advocacy and some have focused wholly on individual advocacy. Thus the advocacy support available to a person with disability differs markedly between the States.

At the same time FaHCSIA has continued a process of review and reform of the National Disability Advocacy Program begun in 2006. This process has been the subject of various false starts and changes in direction, policy and approach over its four year life. Little attention to or coordination with similar processes occurring in other related Commonwealth Programs, for example, HACC and NACAP or in the various State Advocacy Programs has taken place.

The current parliamentary Secretary for Disability, Bill Shorten, is driving change in the funding and delivery of disability services and is taking a strong interest in the disability advocacy sector. He is on record as encouraging the sector to become more cohesive and stronger and louder in its promotion of the rights and interests of people with disabilities. He has been publicly supportive of the creation of a representative disability advocacy body and has expressed interest in hearing DANA proposals for reforming the way disability advocacy is supported, administered and funded in Australia.

d. Past Reviews of the National Disability Advocacy Program

Over the life of the Program, in the Commonwealth jurisdiction alone, reviews or reports have been undertaken in 1993 (2 reports), 1995, 1996 (2 reports), 1999 and 2006. These have been detailed in **Appendix A** to this paper together with the key principles and proposals arising from this work. The information derived from these reviews has been used to inform the key program principles set out in the Principles section below.

The reports and reviews have identified similar problems and made similar recommendations for improvement and reform but the program has continued largely unchanged. The failure of effective reform would thus appear to be linked to:

- Lack of understanding of the importance and necessity for independent disability advocacy
- Lack of adherence to some key principles relating to the role of the Program,
- Inadequate resourcing of advocacy work,
- Poor change management processes,
- Lack of investment in advocacy sector development, professional development and national conferencing,
- Inconsistent and poor support for the advocacy program by a succession of administrations in most jurisdictions.

The failure of leadership and sector development within the disability advocacy sector has also been a contributing factor. Moves were made to address this at the first national conference of the disability advocacy sector in 2007 resulting in the formation of DANA in 2008. The continuing development of DANA since this time provides an important platform for advocacy organisations full engagement in a reform process that will strengthen the role and work of independent advocacy organisations.

All previous reviews struggled to come to a clear view based on a diverse range of views on this aspect of reform from advocacy agencies at the time each review was conducted. DANA has circulated a discussion paper as the preliminary step in development of this proposal and is of the view that there is a new context that suggests a new approach for a more integrated and nationally consistent approach.

The experience of DANA and its member agencies over this period is that the administration of advocacy has suffered from its marginalisation within the National Disability Agreement (formerly CSTDA) negotiations and reforms and that attempts to bring reform have demonstrated a clear lack of understanding about how an effective independent advocacy program should operate. This has led to some states cutting funding to disability advocacy organisations (South Australia cut whole program in 2007 and Victoria made significant cuts to the program in early 1990') some states failing to fund or providing minimal funding to individual advocacy (ACT and Qld respectively) and the Commonwealth proposing and then dropping radical reforms in 2006 because they disregarded local knowledge and experience within the sector.

e. National Disability Strategy

At the same time the Government is focusing on the development of a National Disability Strategy that addresses the social inclusion goals of government and the rights of people with disabilities as described in the UN Convention on the Rights of Persons with Disabilities (CRPD). Advocacy support enables and empowers people with disabilities to assert their rights and demand inclusion. The Australian community encourages and rewards those who confidently and actively pursue their own interests. Government protection and rights mechanisms assume that people have the capability and resources to complain about injustice, discrimination and exclusion when this is their experience. To address the government's stated goals of inclusion and rights protection, the planned national disability strategy must therefore incorporate the availability of individual advocacy support and a strong systemic advocacy presence for people with disabilities at every point in the strategy. Without this the strategy will fail to deliver the desired results to those vulnerable and marginalised people with disabilities who have difficulty communicating their wishes.

f. UN Convention on the Rights of Persons with Disabilities (CRPD)

Australia signed the CRPD on 30 March 2007 and ratified it on 17 July 2008. The terms of the Convention require the Australian government to report to an international monitoring committee on its progress in implementing the Convention in the first 2 years post ratification and thereafter every 5 years. Coherent and comprehensive advocacy support to people with disabilities to assert their rights would assist Australia to meet its international responsibilities under the Convention.

g. National Disability Insurance Scheme

Support is growing for a national scheme that recognises the citizenship rights of all people with disabilities to an assurance from government that their disability support needs will be addressed in a manner that enables their full participation in all areas of community life. The Rudd government has recognised the need for major reform in this area by requesting the Productivity Commission to conduct a public inquiry into long-term disability care and support arrangements. *"There is a widespread view that the current system to support people with disability and their families is deeply flawed and will increasingly be unable to meet people's needs. This has been a consistent finding of recent reports, such as the Way Forward report (Disability Investment Group or DIG 2009a) and the 'SHUT OUT' report (National People with Disabilities and Carer Council 2009)." [Productivity Commission Discussion Paper].*

It is DANA's view that any reforms to the administration of disability funding and support will need to ensure that a strong, independent and viable national disability advocacy program is maintained separately from service provision administration.

h. Self Directed and Individualised Funding Arrangements

There is a significant trend across a number of jurisdictions towards the provision of individualised disability support packages to individuals and their families through either direct payment or brokerage models. Individualised funding models that give people with disabilities and their families more choice and control over how disability support is purchased is a progressive shift that is consistent with the UN Convention on Rights of Persons with Disabilities, and the rhetoric and intent of most Commonwealth and State and Territory Disability Services Legislation.

DANA is concerned that these reforms have not always considered the importance of effective disability advocacy support to ensure that people with disabilities and their families have access to independent advocacy support and advice. It is vital that there is access to both a range of individual advocacy supports as well as systemic advocacy to provide protective mechanisms for more vulnerable people with disabilities in this new funding environment. Any proposed changes to administrative arrangements for disability advocacy support need to need to be considered in the context of these disability service policy shifts.

i. Establishment of DANA

The recent establishment of DANA to strengthen and support disability advocacy organisations in their advocacy work provides, for the first time, an opportunity for the combined wisdom and knowledge of the disability advocacy sector to be harnessed in a systematic fashion for the benefit of people with disabilities. It creates a mechanism for the development and promotion of disability advocacy and quality advocacy practice. It allows advocacy organisations to share information on matters of importance to people with disabilities and to disability advocacy and it provides a vehicle for advocacy organisations to work together to pursue common goals.

The establishment of DANA also provides an opportunity for advocacy agencies together to take the lead in developing an administrative framework for the delivery and oversight of government advocacy funding. The convergence of events detailed above makes this particular point in time significant in terms of the degree of change and of influence that is possible. Without DANA input, the COAG processes are likely to result in decisions taken on the basis of managerial efficiency and effectiveness principles alone. With DANA guidance it may be possible to create the framework and environment for a strong and effective disability advocacy sector to promote and protect and defend the rights and interest of people with disabilities into the future.

3. The Role of Independent Advocacy

a. Benefits to People with Disabilities

Advocacy support is needed to assist the most vulnerable members of our society to assert their rights and interests and have their needs and wants met. People with disabilities are more likely than the general population to experience abuse, homelessness, institutionalisation poverty and social isolation. Many rely on paid carers or family members for their most basic needs, making them extremely vulnerable to the actions and wishes of other people. Many do not understand their rights and entitlements.

Without advocacy support many people with disabilities do not have the knowledge, skills or personal resources either to effectively engage with the systems established to protect and support them or to seek to have those systems changed when they fail to respond appropriately to their concerns or needs. Many, without advocacy support, are unable to convince their families, associates or broader community that they are entitled to live an ordinary life involving meaningful activity, friends and social interaction. When advocacy support is not available or is severely restricted the key decisions in the lives of vast numbers of people with disabilities are taken by others with little regard for their wishes, interests or capabilities and their individuality and capacity to contribute to the community is overlooked and devalued.

The involvement of advocates redresses the power imbalances created through vulnerability so that the voices of people with disabilities are heard and understood. A strong voice leads to others taking notice and taking action in response. A strong voice allows people with disabilities to exercise control over their lives, establish meaningful relationships with other people and to, as far as possible, direct their own engagement in and contribution to the life of the community.

With clear trends of a shift in funding arrangements from block funding to service providers to individualised funding for people with disabilities and their families, the role of independent advocacy support will become increasingly important. There will be a need for independent support to assist people to make informed choices and to monitor and prevent abuse and exploitation. More vulnerable people with disabilities who required assisted decision-making will be particularly reliant on access to independent advocacy support.

b. Why Independence is Important

Advocacy support for people with disabilities comes from many sources: family, friends, government officials, service providers and independent advocacy organisations. All possible sources of advocacy support will from time to time have interests that differ from those of the people with disabilities being supported. Many will have limited capacity, knowledge or resources to devote to the task.

Independent advocacy organisations are vital additions to the advocacy support available because they focus on minimising any potential conflicts of interest and on developing their advocacy skills and expertise to achieve the outcomes desired by people with disabilities. They are not beholden to another set of service or government imperatives and so are able to focus wholly on serving the goals and interests of people with disabilities.

Independent advocacy organisations take on a range of vital tasks. They assist people to advocate for themselves or for others. They represent the interests of people with disabilities in circumstances where others may be conflicted and where people are unable to represent themselves. They seek systemic change using research, evidence collection and dedicated influence mechanisms. Independent advocacy organisations take up the advocacy tasks that others do not see as important or are unwilling or unable to carry out.

DANA recognises the vital importance of independent disability advocacy, by limiting its membership to those non-government advocacy agencies that do not also undertake service delivery. For the purposes of DANA membership and this proposal, advocacy agencies are regarded as including human rights themed information providers.

It is DANA's position that "the delivery of advocacy support to people with disabilities must be provided by agencies that are able to demonstrate independence from all actual, potential or perceived conflicting interests". DANA does not accept that independence can be indicated by the partition of non-advocacy services from advocacy within an organisation. It has also decided, subject to further consultation with the DANA membership, that "to establish independence, an agency needs to have advocacy as its core business and not to be a provider of any of the following services: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, mediation or case management."

NDAP funding is also intended to be limited to independent advocacy organisations.

The National Disability Advocacy Program Quality Improvement Toolkit provides (p21) as an example of evidence of Quality Management Systems "that the agency does not provide direct disability services and is not aligned with any service providers."

This paper will likewise focus on mechanisms to further develop and strengthen the independent disability advocacy sector.

4. Funding for Disability Advocacy

a. Funding Sources

Independent disability advocacy agencies currently receive funding from a wide variety of sources to undertake their disability advocacy work. These include:

i. **National Disability Advocacy Program (NDAP)** – Commonwealth Department of FAHSCIA.

The funding under this Program is predominantly directed to independent advocacy support.

ii. National Disability Agreement (NDA) funding

Each State and Territory, in accordance with the NDA, allocates funding to agencies in the *Disability Services Act* 1987 service category of advocacy, information and print services. The proportion of this funding directed to independent advocacy agencies rather than to service providers varies according to the jurisdiction. For an example of the difficulty in determining the quantum of State funding made available for the provision of independent disability advocacy see **Appendix B**.

iii. **Disability Discrimination Legal Services Program(DDLS)** – Commonwealth Attorney Generals Department

There is an allocation of funding through the Commonwealth Attorney General's Dept for an advocacy service in each State and Territory to support Disability Discrimination Act complaints. The total funding of $961,121 (2008) for this Program goes to agencies that provide independent legal advocacy and there is close cooperation between these agencies and other agencies in the disability advocacy sector.

iv. **Home and Community Care Program (HACC)** – Joint Commonwealth and State Health Department funding

This Program provides funding for individual advocacy for people eligible for HACC services. The HACC target group is people of any age with a profound, severe or moderate disability and their carers. It has been possible to identify some of the HACC funding going to the provision of independent advocacy through information provided by particular disability advocacy organisations [see **Appendix C**] however it has not been possible to determine the totality of HACC Program advocacy funding from the published HACC data. This data aggregates advocacy funding with that provided for counselling, support and information services.

v. **National Aged Care Advocacy Program (NACAP)** – Commonwealth Department of Health and Ageing

This Program provides funding for one agency in each state and territory to deliver independent individual advocacy support for older adults with a disability who are eligible for federally funded aged care services. This includes those living in residential aged care facilities and those receiving community or extended aged care packages. Several of the agencies funded under this program also receive NDAP and/or HACC funding.

vi. **Other State and Local Government Funding** – for example from the Departments of Justice, Sport and Recreation, Mental Health, Education, Local Government, etc

A number of independent advocacy agencies in different jurisdictions have been successful in attracting other State and Local government funding, recurrent and non-recurrent, for activity that extends and strengthens core advocacy work for people with disabilities. This involves funding directed to providing an advocacy role in a particular State portfolio, or within a particular Local Government Area. This paper does not propose any change in the government administration of this kind of funding.

vii. **Other non-government sources** – Philanthropy, fee for service, investments etc

Funding to date, for disability advocacy organisations from these sources, has been extremely limited. While there may be some potential for this to change in the future this issue is regarded as being beyond the scope of this paper.

b. Quantifying the Funding

The following table attempts to summarise the funding from various programs that support the disability advocacy work of independent agencies. The table does not attempt to capture the relevant State/Territory or Commonwealth Program administration funding. **There are significant gaps because information has been difficult to obtain and because DANA has limited resources to undertake extensive research.** There needs to be further research and clarification of funding that is intended by government to provide independent advocacy support both at the program delivery level and at the program administration level.

Advocacy Funding from Various Government Programs (Incomplete Data)

Table 1 – Funding Levels(1) CSTDA (now NDA) NDAP, DDA, HACC, NACAP

	NDAP	State/Territory CSTDA	State CSTDA 07-08	DDLS	NACAP	HACC
		Advocacy, Information, Print Disability 07-08 (5)	Independent Advocacy			07-08
NSW	$3,255,000	$16,274,000	See Table 2 Appendix A			$3.1M(3)
VIC	$3,340,000	$8,961,000	$2,100,000		$503,428	
QLD	$1,763,000	$9,327,000			$406,275	
TAS	$454,000	$2,318,000				
SA	$1,662,500	$1,380,000	NIL			
WA	$1,445,000	$1,508,000	$1,166,417			
ACT	$342,000	$994,000	$97,504		$107,622	$210,769
NT	$318,000	$110,000				
Total	$12,579,500(2)	$40,872,000		$961,121(4)		

Notes:

1. Comprehensive information on funding is difficult to access and needs to be sourced on a government to government basis.
2. From Bill Shorten MP Media Release – Wednesday, June 9, 2009. NB Media Release puts total figure to States at $12.28M instead of $12.59M.
3. HACC funding in NSW has a category for Counselling, Support & Advocacy and Information Services that was funded for over $3.1M in 2007/08.
4. From "Review of Community Legal Services Program – March 2008"
5. From Report on Government Services 2009 Table 14A.5

5. Principles for Designing an Advocacy Program

From the Reports detailed in **Appendix A** and the experience of DANA members and Networks, we have isolated a set of Principles to be used in designing an Advocacy Program and an associated administrative structure that effectively responds to the advocacy needs and interests of people with disabilities.

The Key Principles are as follows:

Principle 1

Government should provide core recurrent advocacy funding on the basis that independent advocacy is a fundamental and essential support for vulnerable people with disabilities.

Principle 2

Program administration and funding should be separate from political or government influence because advocacy is commonly directed against government agencies or services provided under government funded programs.

Principle 3

To minimise the possibility or the perception of conflict of interest, advocacy support should be provided only by dedicated advocacy organisations that do not also undertake service provision.

Principle 4

Individual advocacy support should be available in a variety of forms to all people with disability.

Principle 5

Systemic advocacy capacity should exist in each state/territory to respond to the range of issues that impact on the rights, interests and needs of people with disabilities.

Principle 6

Specialist advocacy support and advice should be available across Australia for specific population groups and where specific advocacy knowledge is required.

Principle 7

Advocacy organisations should be formed in consultation with and remain connected to local communities.

Principle 8

Advocacy organisation funding should provide for advocacy development through:

- Making connections between individual and system advocacy effort

- Collaborating around systemic issues at regional, state and national levels
- Developing skills, knowledge and expertise across the sector
- Developing strong and effective bodies to advocate for advocacy.

Principle 9

Advocacy organisation funding should provide for the development of relationships with key organisations and agencies including:

- Disability service providers, carer/family organisations and government disability administration.
- Generalist advocacy providers e.g. Legal Aid, Welfare Rights, Tenants Union, Consumer Protection, Financial Advice, COSS's, etc
- Statutory oversight bodies e.g. Public Advocates, Guardianship Admin, and Human Rights Commissions.

Principle 10

Advocacy organisation funding should be at a level to ensure the viability and sustainability of the organisation and make provision for:

- indexation and growth,
- movement in State/Territory Awards
- safe and healthy working conditions for staff
- access for all people with disabilities
- costs arising from the geographic location or reach of the organisation.

Principle 11

Government funding for the Advocacy Program should respond to the unmet need for advocacy and bear an appropriate relationship to:

- Number of people with disabilities
- Funding for formal disability services
- Funding for formal complaints mechanisms
- The extent of inclusion of people with disabilities in community life.

6. Program Administration

a. Government Administration

i. Which Jurisdiction?

DANA member agencies across the country have varying experiences in relation to Commonwealth and State involvement in advocacy administration. Agencies in some States have had positive experiences with State funding bodies and in other States there has been a total failure by the State government to fund or support advocacy. Much has depended on the particular culture, leadership, political perspective or personalities involved in the State/Territory parliament and bureaucracy at the relevant time. This has led to different views across the advocacy sector about which arm of government should fund advocacy into the future. Below are some of the arguments advanced in favour of or against the different options.

Commonwealth responsibility

Advantages:

- Consistency across all States
- Minimises conflicts of interest that relate to advocacy against the funding source as States are the primary funder and sometimes provider of services to more vulnerable people with disabilities.
- Importance of the Commonwealth role in leading on policy and funding for human rights and constitutional protection for Australian citizens.

Disadvantages:

- Remoteness of administration from the point of delivery of advocacy support leading to minimal engagement in or local knowledge of the Program by the funder.
- Lack of opportunities for direct feedback from people with disabilities about the effectiveness and availability of advocacy.

State Responsibility

Advantages:

- Better local knowledge and capacity to engage with advocacy agency
- Better capacity to monitor effectiveness of the advocacy effort and to indentify unmet need for advocacy
- Greater capacity to influence political priorities and lobby for advocacy resources.

Disadvantages:

- Conflict of interest for the State administration of advocacy and as well as funding and/or providing the bulk of disability services
- Inconsistency of access to and development of advocacy support between different state jurisdictions.

Joint Commonwealth/State Government

Advantages:

- Commonwealth leadership and consistency of program directions combined with state knowledge and monitoring capacity
- Improved protection for advocacy services from political funding decisions in one jurisdiction or the other – i.e. If a State defunds advocacy, Commonwealth funding can still sustain some advocacy effort for people with disability in that State
- Joint funding responsibility creates a degree of joint accountability to advocacy funding.

Disadvantages

- Failure of coordination and collaboration between Commonwealth and State administrations
- Inequitable access to advocacy support across different jurisdictions.

ii. **Which Department?**

Some discussions in earlier reports and submissions from DANA members have presented strong views about which area of government is most suited to administer the advocacy program. These perspectives are usually based either on ideological or philosophical positions or on positive or negative experiences of existing disability service administrations. Having an existing contractual relationship with a particular government department can make it easier to tap into additional funding and grants through that department and may be an important element in guiding agency thinking about which department is most advantageous.

Disability Services/Community Services

Advantages

iii. Understanding and knowledge of disability, regulatory and service frameworks and the needs of people with disability
iv. An appreciation of the need for a voice for the vulnerable people who access their programs
v. The size of government expenditure in this portfolio and its close alignment with community sector culture could lead to additional funding opportunities.

Disadvantages

- Conflict of interest arising from advocacy against the funding body
- Alignment with disability service provision rather than a rights or justice based alignment.

Health

Advantages

- The size of government expenditure in this portfolio and its close alignment with aged care and HACC administration could lead to additional funding opportunities. HACC program is consistently experiencing 8%-9% growth per annum.

Disadvantages

- Alignment with the medical model of service provision rather than a rights or justice based alignment
- The focus in the health portfolio on crisis and short term care does not align well with working towards long term support.

Attorney General's/Justice

Advantages

- Alignment with rights or justice based focus
- No conflict of interest arising from advocacy against service providers
- Greater understanding of an advocacy approach.

Disadvantages

- Limited understanding of the needs and interests of people with disabilities and of the service and regulatory framework impacting on their lives
- The small size and lack of connection of the Advocacy Program to other Programs administered by the Department.

b. Independent Statutory Body

Advantages

- Advocacy specialists to administer the Program
- One accountability and reporting framework for advocacy agencies
- Capacity to engage both Commonwealth and State involvement and commitment
- Strengths the capacity of advocacy effort to connect with the UNCRPD and National Disability Strategy
- Consistency of advocacy planning and development across the country
- Greater independence from political and government interests
- Greater size leading to greater capacity to generate philanthropic interest.

Disadvantages

- Potential for both arms of government to abdicate responsibility
- Less direct connection with local interests.

There are many examples of government statutory authorities created to exercise functions requiring independence and objectivity. See for example the 'Aged Care Standards and Accreditation Agency Ltd' and the 'Australian Institute of Health and Welfare'. Some of these have governance structures similar to those recommended below. See for example 'Safe Work Australia' [Ref: The *List of Australian Government Bodies and Governance Relationships as at 1 October 2009,* 3rd edition by the Department of Finance and Deregulation].

c. Other Models

In developing the framework proposed below a brief review of the delivery of independent advocacy in other countries of similar cultural background was undertaken. We found a useful international

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analysis undertaken by consultants who were commissioned by Comharile in Ireland who documented their findings in a report titled “Developing Advocacy Services for People with Disabilities”(2004). Reference to a Scottish model for advocacy for people with disabilities drew our attention and was most helpful in providing a potential framework for administration of independent disability advocacy programs in Australia.

The Scottish model consists of the Advocacy Safeguards Agency to administer the program and an advocacy agency peak or network body representing the advocacy support agencies called the Scottish Independent Advocacy Alliance. These two components of the program provide complementary but different functions in promoting access to independent advocacy support to all people with disabilities in Scotland.

The Advocacy Safeguards Agency (ASA) is funded by the Scottish Executive Health Department in furtherance of the Executive’s commitment to independent advocacy. ASA’s purpose is to make sure that good quality independent advocacy is available to anyone in Scotland who needs it. Its main functions include:

1. Development: to assist health and local authority commissioners to develop independent advocacy across Scotland and across all health and social care groups.
2. Evaluation: To ensure that the principles, practice and outcomes of the work done by advocacy organisations are meeting the needs of the people who use them.
3**.** Policy development: To develop policy and good practice in relation to independent advocacy across Scotland.
4. Research**:** To research matters relating to independent advocacy and in particular the effect of independent advocacy on the lives of the people of Scotland.

The Scottish Independent Advocacy Alliance (SIAA) is a registered charity funded by the Scottish Executive Health Department. It is a membership organisation for advocacy groups and other organisations with a commitment to independent advocacy. The SIAA supports the advocacy movement by promoting the importance of diversity and high quality advocacy alongside strong principles and standards across Scotland. It does this by:

- Providing a strong national voice for independent advocacy organisations
- Supporting the growth of existing independent advocacy organisations
- Promoting the development of new independent organisations
- Advocacy awareness raising in the community and training for advocates.

7. A New Administrative and Leadership Framework for Advocacy

a. A new Statutory Advocacy Authority

This paper proposes the creation of an administrative and leadership framework for the independent disability advocacy sector that is different to anything previously proposed. It is advanced in a context where there is a commitment to reforms around shared Commonwealth and State responsibilities in disability and aged services.

The framework includes a new national approach to the administration of advocacy program funding through the creation of a Statutory Advocacy Authority coupled with a commitment to support leadership and advocacy for the sector through recurrent funding of a national body representing advocacy agencies across all jurisdictions (DANA). Such a model is proposed on the basis that it better protects the independence of advocacy from the service provision, managerial and policy interests of government and encourages a strong sector voice to advocate for the protection and promotion of an effective advocacy effort for all Australians who are at risk of human rights violations or abuse and neglect.

The proposed new Statutory Advocacy Authority would be established under legislation and responsible to a Board including both State and Federal Government representation. It would be tasked with providing advocacy with a strong voice at the government level and with presiding over an advocacy program which conforms to the Principles identified above as necessary to sustaining into the future a high quality and effective advocacy program for people with disabilities. Such an Authority, properly constituted and funded, would, through driving quality improvements to advocacy, also drive a culture of respect for and inclusion of people with disabilities in the life of the community.

The functions of the proposed new authority would be as follows:

- Promotion of the value and importance of independent advocacy
- Advocacy sector planning and development including identification of demand and development of comprehensive Program framework incorporating the elements indentified in the Principles above
- Management of core recurrent advocacy funding perhaps via State based officers
- Development and Implementation of a single Performance Reporting and Quality Assurance Framework for advocacy providers
- Research in relation to advocacy practice, administration and demand
- Influence Government policy development and implementation in favour of advocacy.

b. Resourcing the Authority and its Advocacy Programs

Initially the Authority would manage the funding that is made available for independent advocacy for people with disabilities of any age via the NDAP, HACC and the State NDA Advocacy programs. The aims and directions of these programs are broadly interchangeable so a single funding body would significantly reduce duplication of Program management, accountability and sector consultation functions. Discussion should then occur with the relevant departments and advocacy organisations involved with the NACAP and DDLS Programs to determine whether these Programs and the program beneficiaries would benefit more by being administered by a specialist advocacy authority.

The Authority, through research and consultation, would identify the gaps in and unmet need for advocacy support and develop a plan to progressively respond to this so. Over the period of the plan government funding would eventually move to a level that bears an appropriate relationship to the factors itemised at Principle 11 above i.e. the number of people with disabilities, the funding provided for formal disability services, the funding made available for formal complaints mechanisms and the extent of inclusion of people with disabilities in community life. The Authority would also work to build philanthropic interest in providing funding for advocacy.

The Authority would not become involved in Program management for:

- Information services (other than human rights focused information service). These are excluded on the basis that stand alone information provision is a specialised service type requiring different parameters of operation and different professional expertise and oversight
- Offices of the Public Advocate and Public Guardian. These are excluded because they undertake statutory mandated advocacy functions.
- Specific purpose or project State or Local Government funded advocacy. These are excluded on the basis that States must retain the autonomy to address State or regional need or priorities
- Advocacy for carers due to the conflicts which may exist between the interests of people with disabilities and the interests of carers.

Funding for administering the Authority would initially be drawn from the funding currently used to administer the various Commonwealth (NDAP), State and Territory (NDA) and HACC Programs. It would then progressively to move to a level commensurate with functions of the agency.

The Authority would be governed by a Board consisting of Commonwealth and State Government representatives; DANA, AFDO and ACOSS representatives and independent advocacy experts. At a minimum the staff would include an Advocacy Commissioner, policy and community development staff and program administration staff, possibly located in the States

c. A Representative Body for Advocacy

This paper also proposes that recurrent funding be made available for DANA to provide leadership and a strong national voice for the independent disability advocacy sector in:

- National level debates on current and future advocacy and disability practice and policy,
- Development of and quality improvement for the delivery of advocacy support

For further information about DANA please see the DANA Constitution and Strategic Plan available on the DANA website www.dana.org.au.

d. Recommendations for Moving Forward

1. **A working group of Commonwealth and State administrators in relevant programs meet with representatives of DANA to discuss this proposal prior to any decisions being taken to realign current funding arrangements for independent advocacy.**
2. **A feasibility study is undertaken to map out the scope of the DANA proposal for a separate statutory authority and a timeframe for implementation. This should also include consideration of the possibility of an interim administrative structure while appropriate steps are taken to establish a new administrative framework.**
3. **All jurisdictions cooperate in identifying the funding in their current programs that might best sit within an independent advocacy program. This includes both funding to agencies for advocacy support as well as administration funding.**
4. **Government recognise DANA as the representative body for the independent disability advocacy sector and provide it with interim secretariat funding pending finalisation of the Review of the Disability Secretariat Program.**
5. **Government commit to progressively moving towards a level of funding for advocacy that responds to the unmet need for independent advocacy.**

Appendix A

History of Reviews of the National Disability Advocacy Program

Since the creation of an independent disability advocacy program as an element of government programs for people with disabilities arising out of the Review of the Handicapped Persons' Assistance Act (1983), a number of national reviews of the disability advocacy program have taken place. Five Citizen Advocacy Programs were funded as part of the National Demonstration Program that commenced in 1993. This was an outcome of the "New Directions" report (1995) that emerged out of the 1983 Handicapped Persons Assistance Act Review. A further 11 advocacy programs were added to the Demonstration Project and the review of these programs "offered little in the way of useful data and analysis" according to a 1996 departmental briefing paper.

The Disability Services Act 1986 specified a service type for advocacy and information services and defined 3 forms of advocacy…

- Self Advocacy
- Citizen Advocacy
- Group advocacy.

In 1991, the Commonwealth/State Disability Agreement restructured Commonwealth and State program responsibilities with the Advocacy and Information Services remaining as the only service type that was a dual responsibility of both state and commonwealth governments.

In 1992, the Disability Discrimination Act (Commonwealth) was introduced to outlaw discrimination on the grounds of disability.

In 1993, the Disability Advisory Council of Australia commissioned a report that was funded by the then Dept of Health, Housing, Local Government and Community Services. The report, *Safeguarding Advocacy for People with Disabilities in Australia (Judith Cross & Lorraine Zeni)* affirmed that "governments must be involved in the protection of vulnerable citizens and…have a responsibility to ensure advancement of changes that impact on the oppression to which these citizens are exposed". Key recommendations from this report relevant to this paper include:

- Both Commonwealth and State Government should be involved in funding advocacy;
- Conflict of interest to be minimised by preference for funding to go to independent advocacy organisations;
- Funding for independent advocacy and informal advocacy should be increased;
- Prioritisation of funding for people with disabilities who are most vulnerable;
- Advocacy funding for people with disabilities from non-English speaking background and need to investigate specific advocacy funding for people with disabilities from Aboriginal and Torres Strait Islander peoples living in both rural and urban settings;
- Dept should fund advocacy development; and
- Committee should be funded to create an alternative evaluation approach for the disability advocacy sector.

In addition to affirming these recommendations, DACA also recommended that:

- Increased funding should be based on identified need by state and territory;
- New "growth money" should be directed towards advocacy based on a reasonable proportion of total disability services funding;
- Need to explore diversification of funding base for advocacy;
- Need to explore an alternative to funding advocacy through the department responsible for funding disability service provision to minimise conflict of interest.

Also in 1993, a more academic report produced for the WA State Office by Errol Cocks and Gordon Duffy advocated for a strong values base for the disability advocacy work and linked this to Wolf Wolfensberger's work in this area. A key point that is relevant to this discussion paper is the clear distinction drawn between advocacy support and complaints mechanisms. This Report also recommended that:

1. Govt should see advocacy as a fundamental and essential safeguard for vulnerable people, not secondary to service provision.
2. Role of Govt should emphasise its funding and maintenance of advocacy and not its control – it should be recognised in its difference from human services with primary accountability being to people with disabilities.
3. Govt should legitimately provide and support a variety of protective measures which are not to be confused with advocacy but may be used by advocates. Govt should also separately from advocacy, recognise and support peak and representative bodies.
4. Expenditure – proportional to four factors based on the principle of risk insurance.
    a. Expenditure should be proportional to spending on formal services
    b. Expenditure should be relative to the extent of social turbulence and dislocation
    c. Expenditure should be relative to the development of internal protective measures
    d. Because it is at an early development stage, expenditure on advocacy should be greater.
5. Advocacy should be encouraged to be developed as locally as possible.
6. Govt supported advocacy should be supported by local contribution where appropriate to promote participation of citizens & the community and to enhance independence.
7. Respective roles of Commonwealth and State Governments should be spelt out.

A departmental paper, *Advocacy Programs – Framework for Priorities and Effectiveness* was produced in 1994 and endorsed by the then Minister, Brian Howe. This document emphasised:

- Commonwealth government commitment to a strong advocacy system in Australia;
- Support for a variety of approaches to advocacy;
- Support for linkages between advocacy groups with similar interests;
- Preference for a planned needs based approach to new funding for advocacy over a submission based approach.

This Framework was subsumed by the National Advocacy Workshop held in Sydney in 1994 with 85 participants from across Australia. This workshop agreed to:

- a set of 7 key principles for advocacy; and
- the need for a specific framework for evaluation of advocacy.

MGM Consultants were contracted to develop a framework and a report of this work was produced in 1995 under the title, *Advancing Advocacy*. This report argued for:

- A rationalisation of the range of different advocacy types into 2 basic advocacy types, individual advocacy and systemic advocacy; and
- A recognition that dual funding for advocacy from State and Commonwealth governments ensured that advocacy in each state was less vulnerable to changes of government policy in

this area, but that there was a need for greater coordination between both levels of government to minimise duplication in accountability requirements.

In 1996, the Australian Law Reform Commission produced a report, *Making Rights Count: Services for People with a Disability [Australian Law Reform Commission Report No. 79]* recommended:

- That the independence of advocacy would be strengthened if administration of the program was moved from the then Dept of Health and Family Services to a “central agency” (no agency was specified);
- Support for MGM proposal that advocacy be divided into two models of advocacy – individual and systemic advocacy; and
- Establishment of a separate set of standards for individual and systemic advocacy programs.

The first major evaluation of the Commonwealth State & Territories Disability Agreement (CSTDA) by Prof. Anna Yeatman (*Getting Real)* in 1996 highlighted the need for:

- Clarification of the confusion in government and sector between advisory bodies, representative groups and disability advocacy groups. The separate and beneficial roles of each needs to be clarified and better defined;
- Greater emphasis of the advocacy program on consumers of disability services;
- Advocacy program to receive better policy and planning attention by government;
- Viability of funding for agencies providing advocacy support;
- A combined advocacy/complaints model for advocacy program similar to that in New Zealand be adopted. (NB. – The New Zealand model is a health and disability service consumers’ complaints and advocacy program.) However, the report cautions about the capacity to adapt this model to the Australian federal structure of Commonwealth & State relations;
- Both levels of government to continue to share joint funding responsibility for the development of advocacy.

The 1999 National Disability Advocacy Program Review recommended:

- The interests of families be incorporated into the work of advocacy organisations;
- Two categories of advocacy be adopted for the program, individual and systemic advocacy, with an increased shift towards provision of individual advocacy;
- Active coordination between Commonwealth and State government administrations that fund disability advocacy to minimise duplication and address gaps;
- That there be a more equitable (re)distribution of resources between states;
- That there be a component of funding for advocacy development, training & networking;
- That performance indicators and output and outcome measures be developed for the program; and
- That a code of practice be developed for advocacy organisations.

National Disability Advocacy Program reform was initiated by FaHCSIA in 2006 with key proposed reforms being:

- Equitable access to (redistribution of) advocacy funding to cover all regions across Australia;
- Increase generalist individual advocacy funding and redistribution of resources at expense of systemic advocacy, citizen advocacy and specialist advocacy through tender process across the program;
- Introduction of a independent quality audits and performance management system.

Appendix B

State Advocacy Funding – NDA (formerly CSTDA) – NSW

The NSW State Government has broken down their funding in the table below into various categories that includes peak agency funding as a category. The category for Combined Advocacy and Information Services is directed to both independent advocacy agencies as well as larger multi-service providers, some 40 (approx) in total. It is unclear therefore how much funding is dedicated to independent advocacy.

Table 2. New South Wales State Government Breakdown of Funding (Source?)

Service Type	**2008/09 Funding**
Individual Advocacy	$1.8M
Information Services	$2.3M
Combined Advocacy & Information Services	$2.9M
Peak Activities	$1.8M
Print Disability	$363,000
TOTAL	$9.16M

Appendix C

HACC Funding for Advocacy

Table 3 identifies some of the funding for advocacy for people with disabilities under the HACC Program. Much of this goes to agencies that also receive funding to provide independent disability advocacy under the National Disability Advocacy Program or the NDA State/territory equivalent program.

In addition to the funding identified in the table below, there is a significant amount of funding in the HACC program that is supporting advocacy within a service type that includes counselling, support and information services. In the NSW 2008 Annual Report for DADHC there is a total of $3,160,191 identified in this category. Some of this funding is directed to independent disability advocacy agencies. Some disability advocacy agencies also receive funding, $530,850, under a category called "other support".

Table 3

HACC funding for independent advocacy Organisations

Queensland Aged and Disability Advocacy	$948, 373.00
Advocacy Tasmania	$380, 000.00
ACT Disability Aged and Carer Advocacy Service	$210, 769.00
AdvoCare (WA)	$359, 813.00
RIAC	$242, 572.00
DAIS	$94,200
DCLS Aged and Disabilty Rights Team	$52, 099.00