Submission to the Productivity Commission

in Response to the Draft Report about Disability Care and Support

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1. Introduction

The Disability Advocacy and Complaints Service of South Australia Inc. (DACSSA Inc.) is a Commonwealth funded disability advocacy agency, which is managed by a Board of Management of people with disabilities. Our agency is part of the National Disability Advocacy Program funded by the Department of Families, Housing and Community Services and Indigenous Affairs (FaHCSIA).

Disability Advocacy and Complaints Service of South Australia Inc. is funded to deliver individual and systemic advocacy to people with disabilities and their families. Our clients come from all socio-economic backgrounds. Anyone with a disability, including anyone with a mental health problem, can access our service if they have a complaint or grievance related to their disability.

Wherever possible we act on the expressed wishes of the person with a disability.

We would like to take the opportunity to thank the previous Parliamentary Secretary for Disability Services, the Hon Bill Shorten, and the Productivity Commission for the opportunity to investigate a new funding system. We would also like to thank the many advocates for pushing for a change to the funding system. Our current system is more like a lottery and does not meet the needs of so many people with disabilities.

It urgently needs fixing!!

2. Introduction to our Response

Our response to the Draft Report will focus predominantly on the role individual advocacy services will have to play in the new system.

While we are commenting on some of the issues raised and clarifications sought by the Productivity Commission, those responses are found in the response of the Australian Federation of Disability Organisations (AFDO). Our organization went out to country areas in Port Augusta and Whyalla and consulted with carers and people with disabilities about the Draft Report. The result of these consultations has been passed on to AFDO who no doubt will incorporate these responses into their submission.

This submission is focused on the role of advocacy, because we believe that advocacy has only been mentioned as a side issue under DSOs in the Draft Report and this does not reflect the role of disability advocacy agencies currently operating in Australia.

In summary we are recommending that:

1. **A new structure (a Statutory Advocacy Authority) be developed to fund and administer disability advocacy services throughout Australia, and for DANA Pty Ltd to assist agencies to develop first class practices and be the voice of disability advocacy services;**

2. **The new structure be independent from disability services delivery;**

3. **That users of disability advocacy services ought not to have to pay for the service;**

4. **The NDIA become the collector of funding for disability advocacy services and passes this funding on to the Statutory Advocacy Authority;**

5. **Disability advocacy services have a huge role to play in monitoring service standards under the NDIS and in assisting people with disabilities to air their grievances with services and the NDIS itself.**

3. Our Work

Our agency is serving around 600 people with disabilities and mental health issues per year. We are dealing with very simple requests for advocacy to increase care hours or very complicated matters to do with disability discrimination and Guardianship and Administration issues as well as mental health orders before the Guardianship Board in South Australia.

We may deal with discrimination in education because a child has been evicted from a school and cannot access education anymore, people who have lost their jobs as a result of discrimination on the basis of their disability, with mothers who had their children removed at birth because they have a disability and are not deemed to be able to look after their child, and with elderly people whose relatives want to declare them incapable of making decisions for themselves.

Our work is based and guided by the UN Convention on the Rights of People with Disabilities. Our team members all have a disability, our Board members all have a disability and we are following the motto: NOTHING ABOUT US WITHOUT US.

Most of our clients do not have the finances to pay us for our work, we are currently funded by the Commonwealth Government under the National Disability Advocacy Program.

Our Board, our members and most of the people with disabilities we are assisting value our independence. We do not provide any services that may create a conflict of interest for us. That means that we are not providing any other services to people with disabilities, other than advocacy.

4. The Importance of Independence and Freedom of Conflict of Interest

In South Australia we have a Disability Discrimination Legal Service, which is managed by a large welfare organisation. It is attached to a Community Legal Service. In one year we referred six cases to this centre, four were rejected on the basis of conflict of interest.

In one case a person with a disability was discriminated against by the organisation managing the Disability Discrimination Legal Service. In another case a vision impaired person got thrown out of a taxi because he refused to put his dog in the back of the car. The taxi driver was represented by the Community Legal Service hence the person with disability could not access any legal assistance.

We have not had any success with this Disability Discrimination Legal Service, which is the only one in South Australia and SA people with disabilities are missing out on free legal advice in discrimination matters.

Disability Service Organisations which provide in-home care or respite services, or even those who broker services are often respondents in our advocacy work. How can a person expect to get justice if the same people providing the service also provide advocacy. Certainly initial complaints procedures can and should be dealt with by the organisation, but what if there is no satisfactory outcome? How could a service provider, for example, provide advocacy for a person who is complaining about a competing service provider? Would there not be a conflict of interest?

We often find in the aged care sector that some agencies provide a miserable in-home service in order to convince the older person to move into a nursing home. How could such an older person trust them to resolve their complaint about the miserable in-home service?

Even if we were to develop other services such as providing information about available services, assistance with managing self managed care packages, assisting a person to identify their needs for assessments, there could be a conflict of interest. If we are not covering all that is possible, or people want to complain that we did not adequately assess their needs, they would have no one to turn to. Advocacy agencies have traditionally provided assistance to people with disabilities to **question** assessments outcomes rather than assessing people for their needs.

We certainly provide any information we have about available services but we are using someone else's database and have never had the capacity to establish, update and maintain a database which contains all the available disability services/organisations. This requires specialist knowledge and here in SA it is done by the Disability Information and Resource Centre, which employs a staff contingence of at least five people for the task.

Disability Advocacy must remain independent and free of conflict of interest.

We are members of the Disability Advocacy Network Australia Pty Ltd (DANA). DANA has developed a paper about the future of advocacy and we have taken the liberty to repeat some of what was said in their paper. Those citations will be reproduced in italics.

In regards to the importance of independence of disability advocacy agencies DANA writes:

> *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.*
>
> *National Disability Advocacy Program (NDAP) funding is also limited to independent advocacy organisations.*

5. Tasks of Disability Advocates

Our agency works across all ages, all disabilities (including mental health), and all areas of life. We are restricted by our inability to give legal advice, yet we are working in a number of jurisdictions such as the Tenancy Tribunal, Family Reunification and Family Care meetings, Guardianship Board matters, Mental Health Act, Disability Discrimination and Equal Opportunity Tribunals.

We assist in matters across the whole life span such as

- Accessing early intervention services for children
- Education access
- Employment issues
- Accommodation issues
- Abuse and Neglect issues
- Accessing aids and equipment
- Accessing adequate health care
- Advocating for independent living
- Access to respite services
- Assisting with informal care arrangements with family/social support
- Access to the community
- Recreational activities
- Access to Rights and assisting a person to represent their views
- Monitoring service policies and procedures
- Access to transport
- Financial policies and procedures and access to an adequate income – subsidies and entitlements

We are not aware of any single service provider or DSO which could provide expertise, advice and advocacy over the full range of our activities. We are not restricted to disability specific services, we are also working with mainstream organisations and institutions.

Our advocates need a working knowledge of all disabilities. It is not easy to work with someone with a brain injury who has a memory problem and calls twenty times per day because they have forgotten that they called already.

It is sometimes difficult to work with people who have autism and are unable to express themselves. We need to provide access to AUSLAN interpreters and have to provide all our information in a format which is accessible to vision impaired people and to people with intellectual disabilities who may not be able to read and write.

It requires a great deal of training to deal with people with mental health issues.

DANA describes the role of advocacy as follows:

> *Advocacy support is needed to assist those 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 disability 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 direct their own engagement in and contribution to the life of the community.*

6. Where in the NDIS does Disability Advocacy fit?

While advocacy constitutes a service to people with disabilities, it is different from other DSOs in that it is restricted to providing advocacy as the only service unless a conflict of interest may arise.

Hence Disability Advocacy needs its own place in a way parallel to all that the NDIS is offering. Disability Advocacy will not restrict itself to only working with people eligible for the NDIS. Disability Advocacy will work with people involved in the Mental Health medical system, with people in

Nursing Homes (aged care) and with people whose disabilities may not warrant specialist services or in-home care, but who have been discriminated against in the workplace, for example.

Therefore it seems that only part of the funding should come from the NDIS, and other parts must still be provided by either the governments, the aged care sector and the health sectors and possibly some of the funding through the Attorney General's Department.

This would make it very difficult to govern.

After extensive consultations with the current disability advocacy sector DANA has identified the following agreed principles:

> *DANA members and Networks, have been derived 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:*
>
> 1. *Government to provide core advocacy funding on the basis that independent advocacy is a fundamental and essential support for vulnerable people with disabilities*
>
> 2. *Program administration and funding to be separate from political or government influence because advocacy is commonly directed against government agencies or service provided under government funded programs.*
>
> 3. *Advocacy support provision to be restricted to dedicated advocacy organisations that do not incorporate service provision to minimise the possibility of conflict of interest.*
>
> 4. *Individual advocacy support including citizen advocacy to be equally available across the nation.*
>
> 5. *Systemic advocacy including family advocacy capacity to exist in each state/territory to respond to the range of issues that impact on the rights, interests and needs of people with disability.*
>
> 6. *Specialist advocacy support and advice to be available across Australia for specific population groups and where specific advocacy knowledge is required eg in the areas of the law, cultural diversity, disability specific and issue specific etc.*
>
> 7. *Advocacy organisations to be formed in consultation with and remain connected to local communities*
>
> 8. *Advocacy organisation funding to incorporate provision 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.*

9. *Advocacy Organisation funding to incorporate provision for development of relationships with key organisations and agencies including :*
    - *Disability service providers, carer/family organisations and government disability administration.*
    - *Generalist advocacy providers eg Legal Aid, Welfare Rights, Tenants Union, Consumer Protection, Financial Advice, COSS's, etc*
    - *Statutory oversight bodies – eg Public Advocates, Guardianship Admin, Human Rights Commissions*
10. *Advocacy Organisation funding to be at a level to ensure the viability and sustainability of the organisations and make provision for*
    - *indexation and growth,*
    - *safe and healthy working conditions for staff,*
    - *access for all people with disabilities*
    - *costs arising from geographic location or reach of the organisation*
11. *Government funding for the Advocacy Program to 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*

DANA has proposed a different model of advocacy provision (see further down). If Disability Advocacy is covering a wider population than that covered by the NDIS and if Disability Advocacy can be considered by the NDIS as one of the avenues to monitor quality and outcomes, as well as providing NDIS users with assistance to follow the complaints procedures, the NDIS should make a contribution to the considerable workload this change to the NDIS will bring for people with disabilities.

On the other hand it may be the NDIA as the main funder for Disability Advocacy who collects contributions from the Mental Health sector, HACC programs and Aged Care, and possibly the Attorney General's Department for a lot of Discrimination work. The NDIA could become the body providing the funding to the Disability Advocacy sector, provided the money comes with no strings attached and is passed on to the by DANA suggested Statutory Advocacy Authority (see page 14).

7. Current Funding Arrangements

DANA identified the following funding arrangements which are available to disability advocacy services.

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

a) <u>National Disability Advocacy Program</u> (NDAP) - *Commonwealth Department of FAHSCIA. The funding under this Program is directed solely to independent advocacy support.*
b) <u>State CSTDA funding:</u> *Each State and Territory, in accordance with the CSTDA, 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 advocacy rather than to information and 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.*
c) <u>Disability Discrimination Legal Services Program</u>*(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 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.*
d) <u>Home and Community Care Program</u> *(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 B] 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.*
e) <u>National Aged Care Advocacy Program</u> *(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.*
f) <u>Other State and Local Government Funding</u> *– 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 funding.

g) *Other non-government sources – Philanthropy, fee for service, investments etc*

8. A New Model for Disability Advocacy Provision and Funding

Based on these principles DANA proposes a model of Disability Advocacy provision which seems to work well in Scotland.

> *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 complimentary 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:*
>
> a) *Development: to assist health and local authority commissioners to develop independent advocacy across Scotland and across all health and social care groups.*
>
> b) *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*
>
> c) *Policy development: To develop policy and good practice in relation to independent advocacy across Scotland.*
>
> d) *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:*
>
> a. *Providing a strong national voice for independent advocacy organisations*
>
> b. *Supporting the growth of existing independent advocacy organisations*
>
> c. *Promoting the development of new independent organisations*

d. *Advocacy awareness raising in the community and training for advocates*

Hence DANA and our agency propose the following:

> *The framework includes a) a new national approach to the administration of advocacy program funding through the creation of a Statutory Advocacy Authority coupled with b) 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.*

i. *DANA and our agency propose the creation of a new Statutory Advocacy Authority under legislation responsible to a Board including both State and Federal Government representation and representation of the NDIS/NDIA Boards. The proposed Authority 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.*

ii. *DANA and our agency also propose 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*

Further details of the proposal can be obtained by reading through the response from DANA Pty Ltd to the Draft Report of the Productivity Commission.

Summary:

Our members are greatly concerned that the Draft report does not fully comprehend the role of Disability Advocacy. Our members and people with disabilities have fought hard and long throughout the eighties to establish disability advocacy services.

Advocacy services have been underfunded and neglected by the Federal Government over the last ten years. Despite increasing client numbers our agency had to make staff members redundant due to no increase in funding yet rising employee costs.

Should this massive change in culture and service delivery occur disability advocacy services will be needed more than ever before.

Our agency fully supports the proposal of DANA Pty Ltd. We want to see a different and more independent way of delivering disability advocacy.

There is a legitimate place for disability advocacy in the NDIS, in particular with the long expertise of disability advocacy providers improving service delivery and monitoring service standards.

Our agency has been instrumental in several service improvements in Public transport, Disability services, Education, which have benefitted all people with disabilities in South Australia, and we want to continue to do so.

Therefore we are recommending that:

1. **A new structure (a Statutory Advocacy Authority) be developed to fund and administer disability advocacy services throughout Australia, and for DANA Pty Ltd to assist agencies to develop first class practices and be the voice of disability advocacy services;**
2. **The new structure be independent from disability services delivery;**
3. **That users of disability advocacy services ought not to have to pay for the service;**
4. **The NDIA become the collector of funding for disability advocacy services and passes this funding on to the Statutory Advocacy Authority;**
5. **Disability advocacy services have a huge role to play in monitoring service standards under the NDIS and in assisting people with disabilities to air their grievances with services and the NDIS itself.**