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**Disability Care and Support**

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Productivity Commission, GPO Box 1428, Canberra City ACT 2601

OR

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## **Submission to the Productivity Commission**

### **Community Consultation Results in Response to the Disability Care and Support Inquiry**

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## 1. Introduction

Dignity for Disability Inc. (D4D) is a political party and an incorporated association, which is managed by a Board of Management of people with disabilities. D4D does not receive any funding. D4D was set up by people with disabilities and parents/relatives of people living with a disability.

In March 2010 a young woman with disabilities was elected into the Upper House by the South Australian Population.

At the end of July 2010 D4D and the Disability Advocacy and Complaints Service of South Australia Inc. undertook a community consultation about the proposed National Disability Insurance Scheme, based on the discussion paper from the Productivity Commission: Inquiry into Disability Support and Care. The participants at the community consultations come from all socio-economic backgrounds, and had a variety of disabilities or were living with someone with a disability.

This submission is the result of our community consultation.

D4D is supporting the introduction of a NDIS and is actively engaged in improving the quality of life and the human rights of people with disabilities. It is obvious from the result in the 2010 South Australian Elections that the wider community in SA is also very supportive of changes to the system. Frankly the current system is not meeting the needs of people with disabilities. It urgently needs fixing!!

We would like to take the opportunity to thank the Parliamentary Secretary for Disability Services, the Hon Bill Shorten, 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.

## 2. Methodology

This submission is based on two community consultations which were held in Adelaide and through questionnaires which were sent out to several networks and people with disabilities and returned to D4D and DACSSA Inc.

The first consultation was a community meeting at which the idea was introduced and the Federal Parliamentary Secretary for Disability Services, Hon Bill Shorten, and Mr Bruce Bonyhady, as well as the Hon Kelly Vincent MLC from South Australia, were speaking about the idea. The audience asked questions and provided some opinions, which the author noted.

The second community consultation was specifically held for the purpose of gathering ideas about a National Disability Insurance Scheme. Not all questions could be discussed but around 50 people were working in small groups to answer some of the questions in the discussion paper.

The questionnaire was developed as a guide for the community consultations and to enable people who were unable to attend to have a say. The questionnaire is attached as attachment 1.

### **3. General Comments**

While this inquiry has received quite a bit of media coverage and has generally been received as a great idea, the time to consult about this idea was too short. Disability advocacy agencies were only able to focus on the consultations from the middle of June onwards, it takes usually around 4 – 6 weeks to organize a consultation and in this case it was too late to consult with rural and regional areas in South Australia.

Collecting the feed back and writing the submission also takes at least 4 weeks, hence this submission has been put together with some haste.

It is very important that the whole population of Australia is made aware of this idea. Only if the whole population stands beside people with disabilities will it be possible to bring about the desired change. There is no doubt that a lot of conversations are still to be held. A well organized consultation time and a commitment to bring the whole community to the table to discuss this idea is essential for the success of this inquiry.

### **4. General Principles**

Any kind of scheme that provides assistance to people with disabilities must be based on the following principles:

1. People with disabilities should be involved in all levels of administering the National Disability Insurance Scheme, as well as in the delivery of training, education, information and assistance for people with disabilities and in all planning stages.
2. There has to be transparency in funding arrangements and appropriate consumer rights protection measures
3. The human rights of people with disabilities have been outlined in the UN Convention on the Rights of People with Disabilities. Regardless what policies or laws are developed, they have to take into account the human rights of people with disabilities.
4. Access to services to enable people with disabilities to function and participate in society must become an entitlement rather than a lottery game. Currently the State and Territories are trying to get away with as little funding as they can provide. The state of available services and accommodation is a national shame. People are missing out on showers, food, even accommodation, and assistance to an unimaginable degree. Any scheme must ensure that people with disabilities are entitled to care, just as unemployed people are entitled to Newstart Allowance, and people with disabilities are entitled to the Disability Support Pension.
5. Any scheme must ensure that all areas of life are covered and worked on in regards to enabling people with disabilities to participate. That includes many other portfolio areas such as employment, education, the legal system, health, recreation and tourism, the arts etc.
6. Any scheme needs to ensure that essential elements of disability policy are also funded, such as schemes to ensure early intervention and the provision of information, policy development and research, the reporting of how Australia conforms to the UN Convention, research about better equipment, etc.
7. Any scheme must fund thorough education and training for all stakeholders
8. Any scheme must ensure that funding is available for disability advocacy and disability discrimination legal services and the continuation of the development of standards.

9. Developing an alternative funding model for disability services provides the opportunity to change the service delivery model. D4D recommends that Australia adopts a Self Managed Funding Model, which will allow people with disabilities to get in charge of their own services and provides them with a maximum choice.

## 5. Questionnaire and Consultations Outcomes

Around forty people participated in the consultation and around twenty five people/families responded to the call to fill in our questionnaire (attachment 1).

Some questions could be answered with more than one option and many respondents chose to use more than one option, hence the numbers vary from question to question.

The Productivity Commission's discussion paper has raised more questions than were responded to in the questionnaire. The reason for this is that there was not enough time to go through all of the questions, and some of them were quite involved and required specialist knowledge to respond to.

We hope that the questions we selected for our questionnaire and the consultation covered the most essential information the Productivity Commission needs from people with disabilities and their families.

### 5.1 Who should be eligible for a National Disability Insurance Scheme?

#### Questionnaire Outcomes

- |                                                                |    |
|----------------------------------------------------------------|----|
| 5.1a) All people with disabilities and mental health problems: | 23 |
| People with disabilities only                                  | 2  |
| 5.1b) People should be eligible from birth and until they die: | 25 |

As the questionnaire responses show most people want eligibility for the NDIS to extend to all people with disabilities, as defined by the UN Convention of the Rights of People with Disabilities, which includes people with mental health problems.

This was also true for people at the consultations. People did not agree that only those with severe and profound disabilities should be eligible. There are many people who have problems with that concept because it will be difficult to determine what a severe and profound disability is.

All people at the consultations also agreed that the scheme should provide for the cost of disability throughout the whole life span. While the income support payments may change, the cost of disability for a person who has lived with a disability all their life does not change when someone turns 65. D4D Inc. knows of many people with disabilities who are living in Residential Aged Care and who are inappropriately treated and dealt with due to their disability. People who were able to lead a fairly independent life are forced to spend their days in bed because there is not enough time to assist them to get out of bed and get ready for the day. People who have intellectual disabilities

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are treated as if they have dementia, which they do not have, and people are not receiving physiotherapy or treatment that may assist them to remain mobile.

Everyone with a disability who resides in Australia should be eligible for the NDIS. This would include refugees and migrants, once Australia has fulfilled its obligation under the UN Convention on the Rights of People with Disabilities and let migrants and refugees with disabilities into our country.

Therefore D4D and participants at the consultations believe that it is important to extend the scheme from birth until death.

## 5.2 How should eligibility be assessed?

### Questionnaire Outcomes

#### 5.2 How should eligibility be assessed?

Anyone who needs assistance to live with a disability should be eligible for support: 23

On the kind of disability people have 2

#### Comments from the questionnaires:

There could be a panel which includes people with disabilities, medical professionals, OTs. Eligibility for funding should be based on a situational analysis of what the needs to fully participate in life are. It should be a bottom up approach.

If a person's needs have been established through other processes such as a Centrelink assessment, there should be a national database which keeps the results of these assessments so that there is no need to start a new assessment process.

#### Comments from the consultations:

There was agreement that eligibility should be based on needs and shaped by the impact of a person's impairment on their daily life. As there are many different kinds of impairment and not one person is the same as another even if they have been diagnosed with the same kind of disability, the NDIS needs to be able to respond to diverse and complex needs, and it needs to be flexible for changing needs throughout a person's life time.

If eligibility is assessed on the basis of needs and functionality (for example, is the person able to get out of bed?) there is no need for a complex assessment of the eligibility. People with disabilities and/or their family members would be able to assess for themselves what kind of assistance they need and for what purpose.

### 5.3 What kind of services should be provided?

#### Questionnaire Outcomes

##### 5.3.1 What kind of services should be provided?

In addition to all assistance needed for individuals with a disability the scheme should also provide community organizations and advocacy agencies with general funding to allow continuation of existing services and for example, early intervention programs, peer support and consumer advisory leadership training: 21

All assistance needed should be part of the scheme 22

##### 5.3.2 Should informal arrangements be part of the scheme?

People with disabilities should have a choice to employ their family members if they wish to. 23

Care must be taken that this scheme is not destroying the volunteer contribution in the disability sector. 23

#### Comments from the consultations:

Several participants felt that volunteers throughout society should be acknowledged for their contributions by giving them tax breaks or a particular amount of their income tax free.

All participants agreed that the person with a disability should have the choice as to whether to include family members or not, but this needs to be monitored so that the person is not just forced to employ relatives when they do not want to.

This is a sensitive issue. None of the participants or questionnaire respondents wanted to exclude informal arrangements from the scheme. At the same time everyone was aware of the risks associated with this option. For example, in some communities/localities it is common for relatives to get employed by service providers and to get paid to deliver assistance. Our agency has had complaints that these relatives are not showing up for work, but the person with a disability cannot say anything because their family loyalty is more important. To prevent such abuse it is very important that a well resourced advocacy program exists which can reach into all areas of Australia, including remote Indigenous communities.

## 5.4 Should income support payments be part of the NDIS?

### Questionnaire Outcomes

Should people also receive income support?

Yes, people should continue to receive their Disability Support Pension, rent relief and other concessions 20

No, all funding for people with disabilities should come out of the scheme.: 4

I am not sure 1

Comment: DSP should stay and be means tested. NDIS money should not be means tested, and concessions given for cost of disability such as mobility allowance should be means test free.

### Comments from the consultations:

As income support is means tested and other groups in the population are also receiving income support, such as the unemployed, young, and ageing people, the participants felt that people with disabilities should also continue to receive their income support separately from the NDIS scheme. The NDIS is really for services, assistance to overcome barriers to participation, whether this be support at home, to get out of bed, or to do shopping or enter education. Income support is for covering one's day to day expenses and is still very much needed by the majority of people with disabilities.

## 5.5 How can we ensure that application and eligibility is dealt with in a fair manner?

### Questionnaire Outcomes

5.5.1 How should people be assessed?

a) Based on medical evidence: 14

b) their ability to do things should be assessed, it needs to be outcome focused and based on functionality 21

c) assessment should be needs based, outcome focused and a simple one off process, directed by the person with a disability 13

d) people should be able to self assess 16

Comments: There really should be an independent body assessing people

**Comments from the consultations:**

Most people at the consultation agreed that application and eligibility could be assessed by peers or the person themselves. We discussed the model of Independent Living Centres in Canada and other countries. If eligibility has been established previously through a Centrelink assessment or other assessments at school or in hospitals then there is really no need to undertake another eligibility assessment.

Application forms should be straight forward, brief, and should simply describe what kind of service someone needs. If there are any doubts about a person's application an independent arbitrator could investigate and ensure that the needs indicated by the person in their application forms are legitimate.

There was agreement that if there was a deterioration of a condition, medical evidence may need to be provided.

5.5.2 How should the assessment process look like?

- a) It should be short and functional, maybe even self assessment 22
- b) it needs to be thorough and should be repeated regularly if clients request this, especially in changing conditions 7
- c) existing assessments should be used, otherwise assessment should be conducted by an independent assessor 5
- d) Government needs to make sure nobody cheats the system 3

**Comments from the consultations:**

As in the questionnaire responses the participants at the consultation also thought that it would be best to have a short assessment process based on what a person needs assistance with. Many agreed that it could be done through self assessment.

Some people were concerned that people may cheat the system and asked for more independent assessments, or at least for more independent evidence that a person really needs the amount of support they have asked for.

D4D Inc. believes that a mixture of assessment methods may be warranted, especially in cases where the needs are complex and the person does not have family or close associates who know what the person needs. D4D Inc. is more concerned about people missing out on services because they do not know what is available.

## 5.6 What kind of safeguards should be implemented?

### Questionnaire Outcomes

Good independent advocacy services must be made available.	18
Reporting against the UN Conventions on the Rights of People with Disability	9
Reporting that enables the disability community to gauge whether the NDIS delivers a better quality of life through standards and quality assurance	12
Independent Living Centres, such as in Canada, which would help in a one stop shop to identify available services, assist people with disabilities to identify their needs and apply for funding, and also provide advocacy when things go wrong.	4

### Comments from the consultations:

All participants agreed that quality independent advocacy services were needed to ensure that people with disabilities can access the services they need. Many also agreed that the NDIS must cover more than just independent service delivery and that the NDIS should be funding mechanisms which monitor the human rights of people with disabilities and develop instruments to report to the UN Convention on the Rights of People with Disabilities.

The concept of Independent Living Centres was discussed here again. They would provide a one stop shop with information assistance to identify the kind of services available, assistance to identify what kind of services are needed and systemic and individual advocacy services, ideally independent from the other service provision.

## 5.7 How should the scheme be financed?

### Questionnaire Outcomes

Everyone should pay through the tax system by adding a component to the GST	14
People should make a contribution by adding to the Medicare Levy, that way only those who can pay are charged	11
A fund like the Future Fund, investment from the government	4
Can it be a combination of GST and Medicare levy?	4
Comment: The NDIS needs to index any CPI increases	

**Comments from the consultations:**

This was a very interesting discussion at the consultation. Participants were divided as to whether they would prefer a contribution of those who are in the workforce and should pay a levy like the Medicare levy or whether they prefer that everybody pays through the GST. That way the NDIS would not be based on a charity principle, because everybody, including people with disabilities in receipt of the NDIS, would make a contribution to it.

The other advantage of a GST like contribution would be that the burden of financing this scheme would not fall on those of working age. In view of a hugely increasing aged population it may be very important to distribute that burden more evenly.

This would also resolve the issue of co-contributions. Everyone has to purchase goods and services, and hence, everyone already makes a co-contribution, based on their income, by purchasing goods and services.

**5.8 How should the scheme be administered?**

**Questionnaire Outcomes**

Independent statutory authority	15
Could be the government as long as the income is safeguarded and not returned into general revenue	2
Federal Government in cooperation with disability organisations and the authority administering the NDIS	7

Comment:

It should be a national body to ease the transferability into other states

**Comments from the consultations:**

There was agreement on the idea that either all levels of government should come together and administer the system or an independent statutory authority. There was concern that if it is only administered by State Governments, that they will over time erode the scheme by taking the money into general revenue. This concern was also raised if it was just the Federal Government administering the NDIS.

Many participants believed that if the administration was done by a statutory authority that the Government would demand more accountability because they want to stay in control of tax payer's money.

Generally there was agreement that any administration system must ensure that the scheme allows for CPI increases of costs and that any funding for services can be transferred to other States and Territories.

## 5.9 Who should assist people to get access to services?

### Questionnaire Outcomes

Independent Living Centres run by people with disabilities	21
Good information systems	6
Medicare	5
Disability Organisations	7
Government	5
local councils	5

### Comments from the consultations:

Participants agreed that people with disabilities should be involved in ensuring access to services and the NDIS. This could be done by developing a similar system such as the Independent Living Centres or by setting up information centres for people with disabilities where everyone can access all the information needed to access all services, including recreation and legal services.

## 5.10 What do you think needs to happen to change the culture of service delivery, so that the person with a disability is at the centre of decision making?

### Questionnaire Outcomes

NDIS is not enough, we need Self Managed Funding to go along with the NDIS	16
NDIS will not change service culture unless government gives up delivering entitlement and services. Government's role should be to monitor quality of service provision. People with disabilities should be making decisions about what they need and who should be delivering the service to them.	11
Good public relations to promote the scheme	6
The system needs to be simplified so all of us can navigate the system and find the services we need.	1
It is a beginning. We need to cut out the middle men and the bureaucracy. Whenever Government funds any services they become incredibly expensive. The same service can be purchased privately for a fraction of the cost.	1

Accountability and advocacy must continue!!

1

Good communication must be warranted between all players.

**Comments from the consultations:**

As the comments from the questionnaires indicate, just introducing the NDIS will not eradicate the issues and barriers people with disabilities are facing every day.

A change of service culture cannot be achieved by simply introducing the NDIS. The NDIS has to go hand in hand with a self managed funding system.